

THE DEVELOPMENT AND TESTING OF A PRACTICE MODEL
WITH FAMILIES BEREAVED DUE TO
SUDDEN INFANT DEATH SYNDROME

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ABSTRACT

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This study was conducted with a dual focus: the development of a practice model with families who had lost a baby due to SIDS and the testing of that model against the conventional counseling approach offered by the NYC SIDS Program.

The social networking model, which was designed according to developmental research guidelines, was based on the consensus findings in the literature, as well as the author's clinical work with more than 500 SIDS families. This model emphasized social support as a key factor in coping with the death, resulting in a crisis intervention approach which sought to sensitize the existing network and create artificial support when necessary.

Using a comparative research design, three primary hypotheses were established: 1. The social networking group would perceive greater social support. 2. The social networking group would experience a less problematic grief process. 3. The social networking group would experience a less problematic blame process.

The data were collected during a one-year period at the Brooklyn Office of the NYC SIDS Program (MHRA). The sample was drawn from 82 infant deaths, resulting in 30 mothers in each group. Randomization occurred after the respondent met the criterion for inclusion, which was the perception of limited support at the first contact point.

Mothers were interviewed at two weeks, three months and six months after the death and the design employed a measure of perceived support, a grief scale and separate indices of self-blame, blaming others and blame by others.

The findings confirmed the primary hypotheses that mothers in the social networking group perceived greater support and experienced less grief and blame.

The data also suggested a sequential model of change in the networking approach, wherein markedly improved perceptions of support coincided temporally with reductions in self-blame and perceived blame by others, followed by reductions in grief and blaming others later on.

Qualitative analysis of case material indicated that within the networking group, mothers whose outcome was not optimal tended to report more concurrent psychiatric and social stressors and a less responsive social network, implying a mutually interactive coping process.

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INTRODUCTION

Chapter I

Over the past decade, the bereavement of more than 70,000 American families due to Sudden Infant Death Syndrome (S.I.D.S.) has emerged as a significant public health/mental health concern throughout our nation. There is increasing empirical evidence that the grief response which accompanies this loss is distinctly severe and extended and a large anecdotal literature frequently notes suicidal and homicidal reactions among parents, as well as the onset or recurrence of major psychiatric illness, substance abuse and stress-related medical conditions. In addition, the mysterious nature of the baby's death in the context of societal expectations and suspicions regarding parenting, generates intense feelings of blame and guilt. These reactions have been implicated in marital dissolution and intergenerational conflict among the bereaved and kin.

The impetus for this study came from the realization that despite the large numbers of families affected, as well as the compelling intensity of this tragedy, the response of the helping professions had been limited and fragmented. With nearly fifty SIDS counseling programs across the country, there appeared to be little consensus

regarding suitable counseling strategies and only a handful of project-based research efforts. Moreover, the existing data base regarding SIDS bereavement was almost exclusively anecdotal with only one attempt to assess the impact of intervention, and the bereavement and crisis intervention literatures were replete with untested assumptions and practices, as well as conceptual limitations and contradictions.

This has been a two-part dissertation consisting of the development of a practice model and its testing in a comparative treatment design. The model emphasizes the key role of social support in coping with SIDS and represents a significant modification of traditional crisis intervention theory and methods. The research hypotheses addressed the central issue of whether increased social support generated by the new model of practice would result in better outcomes.

The writer's involvement with Sudden Infant Death Syndrome began in 1973 when, as a student researcher with the NYC Dept. of Health, he culled the first descriptive profile of SIDS Infants from biostatistical death records. At that time, he became aware of the complete lack of services for such families and seven years later joined the NYC Information and Counseling Project for Sudden Infant Death, which had been estab-

lished in 1976 via legislation mandating Federal funds for such programs.

Since January of 1980, the writer has been employed as Mental Health Consultant to the New York City SIDS Project and during this time, he has had direct clinical experience with over 600 bereaved families, a total which is probably unmatched by any other mental health professional. The project is also mandated to educate and sensitize professionals and the public regarding the nature of crib death, and he has conducted extensive workshops with health and mental health professionals, emergency medical technicians, clergy, funeral directors, etc.

RESEARCH PROBLEM

CHAPTER II

SIDS: DEFINITION AND EPIDEMIOLOGY

The Sudden Infant Death Syndrome (S.I.D.S.), also known as crib death or cot death, is the sudden and unexpected death of an apparently healthy infant whose death remains unexplained following a complete post-mortem examination (Valdes-Dapena, 1980).

SIDS is the largest single cause of postneonatal infant mortality, accounting for approximately 1/3 of all deaths in infants between one month and one year of age. Nearly all studies reported to date revealed incidence figures in the range of 2-3 per 1,000 live births, resulting in a national rate of nearly 7,000 crib deaths per year (Beckwith, 1976).

One of the most consistent and perhaps the single most characteristic feature of SIDS cases is the age distribution. The sparing of very young infants, peak incidence between 2 and 4 months, and rapid decline after the age of 6 months are common to virtually all studies. There is no other known condition with this unique age distribution (Beckwith, 1976).

Regarding the circumstances of death, it has been generally recognized that SIDS is a phenomenon that almost invariably occurs unobserved during periods when the

infant is asleep (Beckwith, 1976).

Nearly all researchers have observed seasonal variations in SIDS incidence, with fewer cases occurring in the summer months (Beckwith, 1976).

Several studies focusing on socioeconomic factors have yielded quite consistent results, with an increased incidence of SIDS in lower income groups (Valdes-Dapena, 1980). However, it is not clear to what extent the influence of socioeconomic factors is independent of other variables such as race and low birth weight.

Virtually every study has shown a male preponderance among SIDS victims. The presumption is that this reflects the general male preponderance in mortality and infectious disease morbidity in infants (Beckwith, 1976), although specific factors predisposing the male to SIDS might exist.

An increased risk of SIDS among low birthweight babies is shown by almost all studies (Valdes-Dapena, 1980).

Other epidemiologic features with more equivocal findings include: multiple births, parental age and parity, feeding histories and genetic factors.

A synthesis of epidemiologic and pathologic findings yields the following analysis. Age and sleep are eligibility factors, in that almost without exception, the

victims of SIDS share these factors. A number of other factors are frequent, but less constantly associated. These, which may influence the threshold or likelihood of occurrence of a SIDS event, may be termed contingency factors. Among these are minor infections, prematurity and low socio-economic status. Death is rapid and silent.

Many current researchers suggest that SIDS probably represents a final common pathway in which many factors act in different ways to impinge on the sleeping infant and precipitate the lethal event (Beckwith, 1976).

To date, over 100 separate hypotheses have been tested, but definitive etiologic or clinically useful findings have been elusive. S.I.D.S. remains, in large measure, a mysterious killer and a diagnosis of ignorance.

Prior to 1976, when SIDS programs were first established, parents who lost a child to crib death were occasionally arrested and imprisoned and almost always left to cope on their own with this unspeakable horror.

When the writer joined the NYC SIDS Program in 1980, the writer recognized the opportunity and challenge of providing social work services to a newly-identified population. There was limited collective practice wisdom at that point, and virtually no systematic studies of SIDS families. The bereavement and crisis intervention literatures were dominated by psychodynamic concepts and prescriptions,

with little empirical evidence to support time-honored, but untested, constructs and techniques.

This dissertation, therefore, arose primarily from the question of how best to help such traumatized families given the above-mentioned limitations in theory and practice. (The premise that SIDS families required at least some professional intervention will be discussed later.) Since these conceptual and clinical shortcomings prompted the need for model development, the specific issues will be detailed in the review of the literature.

This study, in the comparative treatment design used to test the model, also addresses methodologic research issues in the field of bereavement. For example, there are norms of propriety that are incompatible with the systematic gathering of information from grieving persons (Rosenblatt, et al., 1976). Also, recently bereaved persons experience cognitive impairments which can obviate the use of lengthy and structured instruments (Hansell, 1976). Bereavement researchers have noted the lack of consensus regarding which variables to measure, how to measure them and how to conceptualize outcome (Institute of Medicine, 1984).

The resulting limited data base is marked by major gaps in knowledge regarding the process and outcome of grief and mourning, as well as a serious paucity of inter-

vention studies. In particular, risk factors for dysfunctional outcomes are not well-defined and though researchers have focused on conjugal bereavement in adults and parental bereavement in childhood, little is known about the impact and consequences of the death of a sibling, of a child or of one's parents during adulthood. Moreover, most of what is known about bereavement comes from work done in the United States, the United Kingdom, Australia and Israel, usually focusing on White, middle-class persons. There is almost no empirical data addressing the sociocultural variations following death. Lastly, more information is needed regarding the biology of grieving, the long term effects of loss and the impact of death on family systems.

In addition, the promulgation and utilization of bereavement research has been equally problematic. Prominent works, such as Lindemann's parameters for normal grief (1944), Kübler-Ross' stages of mourning (1969) and Parkes' categorization of bereavement reactions (1965) achieved practically universal acceptance among the helping professions despite the lack of empirical validations.

Finally, this dissertation responds to social work's concern with the need to integrate practice and research (Fanshel, 1980; Rosenblatt and Rubin, 1977). As Rothman (1977) states:

The basic researcher in social science and the human services professional are divided by a common need: the effective utilization of social science knowledge. That division has not been without its consequences. Practitioners wait impatiently for researchers to provide information through journals, books, scientific papers at conventions, monographs, and so forth. They believe themselves to be effective communicators of their results and are often puzzled and irritated that the practitioner does not take advantage of what is offered. An undercurrent of tension, mistrust, and lack of confidence pervades the researcher-practitioner relationship, a function of equally pervasive misperceptions of one another's roles and functions (p. 82).

If the fundamental difference is that social scientists are concerned primarily with comprehending society and practitioners with changing society, then the interdependence of these two functions demands some kind of reconciliation and linking process. Again, Rothman (1977) analyzes the dilemma:

The social science researchers have gone into the forest of knowledge, felled many a good and sturdy tree, and displayed the fruits of their good work to one another. A few enterprising, application-minded lumberjacks have dragged some logs to the river and shoved them downstream. Somewhere down river, the practitioners are manning the construction companies. They manage somehow to piece together a few makeshift buildings with what they can that has drifted down the stream, but on the whole, they are sorely lacking in lumber in the various sizes and forms they need to do their work properly. The problem is that someone has forgotten to build the system, while the construction companies continue to make do at the other end (p. 84).

Social work's response to this problematic dichotomy has been to propose a new breed of professional,

variously known as the clinician-researcher or practitioner-scientist, whose role is to condense, repackage and interpret basic knowledge into therapeutic strategies and techniques. The methodology to accompany this role is termed developmental research or model development.

Practice models are engineered via the organization of discrete theoretical elements into a coherent set of action guidelines. Thomas (1978) is emphatic that:

Developmental research may be the single most appropriate model of research for social work, because it consists of methods directed explicitly toward the analysis, development, and evaluation of the very technical means by which social work objectives are achieved (p. 14).

An effectively developed model is one which strives to collect and integrate large amounts of theoretical and empirical evidence into a set of well grounded clinical prescriptions. Beck's cognitive psychotherapy (1976) and Minuchin's structural family therapy (1974) are apt examples. There are different formulations for model development and the more rigorous ones, such as Rothman's R&D (1980), require field testing to validate or revise practice principles. The seminal work of Reid and Epstein (1972) in the development, application and evaluation of task-centered casework is clearly in this tradition. The actual approach used to guide the literature review will be presented in the next chapter.

The testing of the practice model in this study

focused on translating the core conceptual and clinical guidelines into researchable hypotheses. As the review of the literature will indicate, the newly developed model emphasizes the pivotal role of social support in parental coping with crib death, and activating or creating support within the bereaved mother's social network was the primary clinical strategy. To determine the effectiveness of this model would ideally require an experimental research design using a no-treatment control group. However, given the nature of the problem, it was felt that this was not ethically and clinically acceptable so a comparative treatment design was selected. Thus, the social networking approach was compared with conventional bereavement counseling, as the usual service provided by the NYC SIDS program. The key dependent variables were (as in most bereavement studies) grief and (more specific to SIDS) the attributional process. Given the unexplained, mysterious, perhaps suspicious nature of the infant's death, it was frequently observed that self-blame, blaming others or being blamed by others were crucial factors in coping with the loss of the infant. Thus, measures of grief and blame were employed to assess the impact of differential interventions yielding the following research hypotheses:

- 1) Mothers in the social networking group will have

a perception of greater social support than mothers in the conventional counseling group.

2) Mothers in the social networking group will have a less problematic grief response than mothers in the conventional counseling group.

3) Mothers in the social networking group will have a less problematic attribution/blame response than mothers in the conventional counseling group.

The term "less problematic" in hypotheses #2 and #3 is used advisedly since both grief and blame are distressing processes, and establishing a positive outcome in these areas is difficult to determine.

FOOTNOTE:

A fourth hypothesis comparing role functioning for both groups was originally proposed. However, it was subsequently eliminated from the study due to methodologic reasons to be discussed in Chapter IV.

REVIEW OF THE LITERATURE

CHAPTER III

Introduction

This literature review initially sought theoretical and empirical findings within the SIDS literature, which could guide the development of a new practice model. Given the limitations in that knowledge base, the review expanded to search for conceptual and research data in the field of bereavement and in a variety of allied topics. Thus, some of the literature surveyed may not directly relate to the hypotheses proposed to test the model, but were nonetheless necessary in order to derive application concepts and practice principles.

The format used for the review followed the general principles articulated by several developmental researchers, but did not completely utilize the more detailed schema of Rothman's R&D model of research utilization (1980). The following guidelines were used:

- 1) Designation of the relevant social science pool of knowledge
- 2) Retrieval program to survey and synthesize conceptual and research findings, leading to generalizations
- 3) Conversion of the generalization into prescriptive methods or techniques known as "application concepts."

In terms of the pertinent social science data, bereavement, grief and mourning, stress, coping and adaptation, social support, social network and professional helping were specified as practice-relevant issues. These topics are embedded in the fields of thanatology, crisis theory, stress theory, family theory, ego psychology, cognitive theory, systems theory and human ecology, which are themselves variously assigned to the disciplines of sociology, psychology, anthropology, religion, and medicine. Contributions to this wide-ranging literature come from all of the helping professions including: social work, psychology, psychiatry, nursing, medicine, public health and religion.

Application concepts are: (a) founded on research evidence, (b) supported by personal experience and (c) supported by the practice literature. Such concepts are considered to have high potential as intervention strategies but are still at this point, only informed suppositions based on the use of inference and conjecture to reshape a generalization. Empirical testing is thus required to substantiate the observations.

The review is organized under three headings: Bereavement, Grief and Mourning (the crisis) and Coping: Person-in-Environment (the response). In both areas, the traditional and conventional theoretical and empiri-

cal findings are presented and then contrasted with concepts and research which expand, modify or contradict the other material. The third section, Intervention, examines the predominant crisis intervention/bereavement counseling approach with a model based on ecological and systems perspectives. At the end of each section, a list of application concepts is presented, noting the implications for working with SIDS families. These generalizations provide the philosophic, theoretical and clinical bases for the social networking practice model which is explained more fully at the end of this chapter.

The review of the literature in the service of developing a practice model presupposes that professional intervention is indeed necessary and desirable. The horror of Sudden Infant Death Syndrome epitomizes the situational crises which have long been the focus of crisis theory and treatment and might imply that counseling and psychotherapy would be essential in coping. However, there is some evidence that this might not be as clearcut as expected. The recent Institute of Medicine (1984) review of the bereavement literature concluded that the majority of bereaved persons do not seek professional help (and are presumed to recover sufficiently to regain their social roles and psychological balance). Similarly, most SIDS families do not continue to avail themselves

of services after contact was initiated by the clinician.

Yet, it is equally clear that the unexplained nature of SIDS and the likelihood of self and/or other blame results in an almost universal need for professional explanations and reassurance regarding the baby's death. In addition, perhaps because of the heightened potential for deterioration, clinical involvement can help to determine those at-risk, vulnerable persons and families and thereby serve both preventive and early intervention functions.

With this in mind, the writer chose to proceed with the literature review, ultimately incorporating the concept of differential risk into the social networking practice model.

BEREAVEMENT, GRIEF and MOURNING

DEFINITIONS

Although the clinical literature, and common usage, show considerable blurring and overlap regarding these terms, some distinctions may be helpful.

Bereavement refers to a social status, which includes both the period of time following a death and also the state of experiencing grief. Grief is best understood as a complex emotional, cognitive, behavioral and physiologic response to loss, whereas mourning consists of culturally defined expectations and acts that are performed during a designated mourning period (Rosenblatt, 1976). While the distinction between grief and mourning (traceable as far back as Durkheim's "Elementary Forms of Religious Life", 1915) facilitates the study of psychosocial processes so affected by culture, it is important to note that reciprocal influences of personality vis-a-vis mourning and role enactment are also operative. Thus:

All grief behavior by adults will, of course be patterned, modified and perhaps even coerced by culture, and any mourning act may be influenced by the biology or psychology of grief (Rosenblatt, 1976, p. 2).

BEREAVEMENT

Bereavement as part of the human drama has appeared in the literature of all peoples and times, and Carr (1975) has portrayed it as an intrinsic part of life:

The capacity that makes one capable of warm, satisfying relationships, also leaves one vulnerable to sadness, despair, and grief when such relationships are interrupted.... Loss and separation are the recurring themes of human existence and development; bereavement as a matter of degree is an unceasing state (p. 3).

However, only recently have social scientists undertaken direct, systematic studies of bereavement and its effects on individuals and families. There are important findings from the epidemiologist and conceptual contributions from both stress theorists (social science) and crisis theorists (clinical practice).

Epidemiologic Data - Thomas Eliot (1932), an American sociologist, is credited with the first attempt to describe and explain bereavement as a life crisis, with particular focus on responses and patterns of recovery among various families. This early work was amplified by Fulconer (1942), who observed a five-stage recovery process, and by Marris (1958), who depicted the dysfunctional consequences of bereavement in a representative sample of London widows. During the last twenty years, a number of researchers have suggested that bereavement, as a crisis precipitant and risk factor is associated with a higher than expected incidence of medical, psychiatric and social disorders (Clayton, 1982; Maddison, 1967; Shanfield, 1983).

In the area of physical health, a number of pros-

pective studies show an increase in medical symptoms, physician visits, hospitalizations, cigarette smoking, alcohol consumption and use of tranquilizers (Heyman and Gianturco, 1973; Parkes, 1972). The data on mortality also suggest an increase in death from all causes among the bereaved, and that the risk of suicide is similarly increased (Clayton, 1968, 1974, 1982).

Psychosocially, increases in depression and general psychiatric consultation are noted and the syndrome of "pathological grief" is estimated to occur in five percent of the population (Clayton, 1982).

The fact that several studies question the association between bereavement and adverse outcomes (Clayton, 1982; Helsing, et al., 1981) does not refute the potential stressfulness of bereavement, and may serve as evidence of the natural and resilient coping ability of large numbers of persons, as well as the efficacy of preparation provided by cultural and social institutions, and the supportiveness of social networks.

Stress Theory - The Dohrenwends (1980) ask, "What is a Stressful Life Event?" Kastenbaum (1975) queries, "Is Death a Life Crisis," and most scholars and practitioners respond that bereavement is indeed a stressor variable and a hazardous event.

Stress theorists argue over whether to use nomothetic

(normative) or idiographic (subjective) parameters to define stressful life events, and the scales which they construct rate bereavement as a highly stressful crisis situation (Holmes and Rahe, 1967; Horowitz, 1976, 1977). Notably, one index regards the loss of a child as life's most stressful experience (Dohrenwend, 1977).

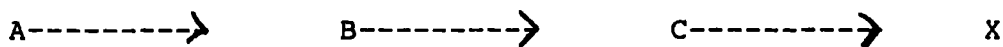
Cognitive and attribution theorists focus on the meaning attached to events and conclude that the significance, real or symbolic, of stressful life events is determined both by one's culture and personality, and subsequent coping is, in turn, affected.

Crisis Theory - Since bereavement may be regarded as the prototype "state of crisis", the numerous concepts and paradigms are presented in that context.

Beginning with Lindemann's (1944) focus on grief, and Caplan's (1964) more general approach, major proponents of crisis theory have included: Lydia Rapoport (1970), Howard Parad (1965, 1974), David Kaplan (1962), Gerald Jacobson (1968), Naomi Golan (1974, 1978, 1980), Larry Smith (1978), Donna Aguilera and Janice Messick (1978), Ann Burgess and Bruce Baldwin (1981).

Reuben Hill's crisis paradigm (1949) has dominated theoretical and clinical thinking for the past thirty

years, and is perhaps the most well-known component of modern crisis theory. Briefly, Hill postulates that a precipitating crisis event (A) interacts with the family's crisis meeting resources (B), which interacts with the definition that the family gives to the event (C), producing the state of crisis (X).



The crisis concept has been defined in systems theory terms as an "upset in a steady state", and is considered by Parad (1974) to be a conceptual device for binding together certain types of problems and needs. He identifies four interlocking phases of the configurations.

- 1) a specific identifiable stressful event
- 2) perception of the event as meaningful and threatening
- 3) disorganization or disequilibrium resulting from the stressful event
- 4) coping and intervention tasks involved in an adaptive or maladaptive resolution (p. 197).

Brandon (1976) regards the crisis state as the normal response to a temporary failure to meet an adaptive challenge.

The Cummings (1962) define crisis as the impact of an event that challenges the individual to change his view of or readapt to the world, himself, or both.

Bloom's panel of experts (1963) considered persons to be in a state of crisis if emotional distress followed a known precipitating event.

David Kaplan (1962) has offered a rather interesting analogy, comparing crises to infectious disease states, which may be superimposed on healthy personalities or on long-term chronic conditions.

Gerald Caplan's (1964) view is perhaps the most oft-quoted:

A crisis is a short period of psychological disequilibrium in a person who confronts a hazardous circumstance that for him constitutes an important problem which he can for the time being neither escape nor solve with his customary problem-solving resources (p. 53).

Crisis events have been organized and classified by a number of writers: Jacobson's (1968) generic vs. individual, Golan's (1974) anticipated vs. unanticipated, Morrice's developmental vs. accidental (1976), Aguilera and Messick's maturational vs. situational (1978), and Shneidman's intra-, inter-, and extra-temporal (1973). Baldwin's five class typology (1978) is the most extensive, but as with other schemas, the basic underlying dimensions which could make the categories mutually exclusive and exhaustive are lacking.

The basic principles of crisis theory may be summarized as follows:

- 1) Crisis situations are initiated by hazardous events.

- 2) Crisis situations are neither illness nor pathological experiences, and have no relation to psychopathology per se.
- 3) Emotional crises occur among the well-adjusted and may reactivate earlier unresolved conflicts. Adaptive crisis resolution may help solve these underlying conflicts.
- 4) Emotional crises are self-limiting events in which the state of active crisis continues for 4-6 weeks and resolution, either adaptive or maladaptive, takes place within that period.
- 5) Each particular type of crisis follows a series of predictable stages.
- 6) During the crisis state, the individual or family has weakened defenses, an enhanced capacity for cognitive and affective learning, and is particularly amenable to help.
- 7) A small external influence during a crisis state can produce disproportionate change in a short period of time when compared to therapeutic change that occurs during non-crisis states.
- 8) Resolution of the crisis is not necessarily determined by previous experience or character structure, but rather is shaped by current psychosocial influences.
- 9) Effective crisis resolution prevents future crises of a similar nature.
(Golan, 1978; Smith, 1978).

GRIEF AND MOURNING - the topic of grief and mourning was first approached by theorists in the beginning of the 20th century, beginning with Abraham (1912) and Freud (1915).

Freud's "Mourning and Melancholia" was published in 1917 and has been regarded as the foundation of the

psychoanalytic view of depression and its relationship to bereavement.

Bowlby (1961), an English psychoanalyst, proposed a theory of grief with a strong neurophysiologic basis, and Parkes (1965), a research psychiatrist, viewed grief as a process of realization and adaption to external reality.

Probably the single most important statement to elaborate on and extend the views of these seminal thinkers was Lindemann's (1944) therapeutic experience with bereaved survivors of the Coconut Grove fire. More than forty years later, his description of the "Symptomatology and Management of Acute Grief" remains a key contribution to the thanatologic literature, and a cornerstone of crisis theory.

The above-mentioned physicians and others have tended to portray grief and mourning in deterministic, linear terms and their "medical model" includes: symptomatology, clinical types, acute, chronic, pathological, delayed, distorted, etc., stages, courses and management. When psychiatrist George Engel (1961) asks, "Is Grief a Disease?" the answer is affirmative.

In his comparative study of grief and mourning in seventy-eight world cultures, Rosenblatt (1976) concluded that:

We have assumed in our research that people everywhere experience the death of close kin as a loss, and mourn that loss. Judging by our findings, our assumptions have been correct (p. 124).

That bereavement is accompanied universally by grief and mourning does not mean that both processes are universally expressed. This point has great clinical significance and will be discussed later.

The grief reaction is extensive and varied, and the manifestations may be seen in four general categories (Moriarty, 1967; Siggins, 1966; Smith, 1975).

- 1) emotional - sadness, anger, guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief and numbness.
- 2) cognitive - disbelief, confusion, preoccupation, sense of presence and hallucinations.
- 3) behavioral - sleep disturbance, appetite disturbance, social withdrawal, avoidance of reminders of deceased, sighing, crying, dreams of deceased, visiting places or carrying objects as reminders of deceased.
- 4) physiologic - hollowness in the stomach, tightness in the chest and throat, oversensitivity to noise, a sense of depersonalization, breathlessness, muscle weakness, lack of energy and dry mouth.

Grief reactions have long been conceptualized in terms of sequential stages of occurrence. Kavanaugh (1972) identified seven phases (shock, disorganization, volatile emotions, guilt, loss and loneliness, relief and reestablishment), and Kübler-Ross (1969) posited five

stages of adjustment (denial, anger, guilt, preparatory grief and "goodbye"). Bowlby (1980) and Parkes (1964) have also provided phasing schemas.

This contribution by grief theorists appears to have been widely adopted for clinical purposes. The professional and lay thanatology literature, numerous presentations on bereavement at conferences and workshops, and the author's training and consultation with hundreds of health and mental health professionals finds that stage theories of grief predominate in current counseling efforts with bereaved families.

Rosell (1970) suggests that the duration of grief depends on the person's ability to form new relationships and to readjust to life without the deceased. Elliot (1978) relates grief to age, separation from the remainder of the nuclear family and degree of dependency on the deceased, and Vernon (1970) posits a clear relationship between length of grief reaction and time elapsed since the death.

The range of grief responses and the stages in which they occur appear to represent the parameters of the process. However, the actual grief reaction for any given individual is also a function of many interrelated factors. Parkes (1972) identifies six areas:

- 1) status in the family
- 2) nature of attachment

- 3) mode of death
- 4) historical antecedents (previous psychosocial functioning
- 5) personality variables
- 6) social variables (ethnicity, religion, etc.).

The determinants of the familial grief response is based, according to Herz (1980), on four factors:

- 1) timing of death in the life cycle
- 2) the nature of death
- 3) openness of the family system
- 4) family position of the deceased (pp. 224-234).

Most extensive formulation of factors affecting the grief process is offered by Rando (1984):

- 1. The unique nature and meaning of the loss sustained or the relationship severed.
- 2. The individual qualities of the relationship lost
- 3. The roles that the deceased occupied in the family or social system of the griever
- 4. The bereaved person's coping behaviors, personality and mental health
- 5. The individual's level of maturity and intelligence
- 6. The individual's past experiences with loss and death
- 7. The individual's social, cultural, ethnic, religious and philosophical backgrounds
- 8. The individual's sex role conditioning
- 9. The individual's age
- 10. The characteristics of the deceased
- 11. The amount of unfinished business between the griever and the deceased
- 12. The individual's perception of the deceased's fulfillment in life
- 13. The circumstances of death (death surround)
- 14. The timelessness of the death
- 15. The individual's perception of preventability
- 16. The sudden vs. expected death
- 17. The length of the illness prior to death
- 18. Anticipatory grief and involvement with the dying patient
- 19. The number, type and quality of secondary losses
- 20. The presence of concurrent crises or stresses
- 21. The individual's support system and the acceptance and assistance of its members (pp. 43-69).

Early theorists viewed "abnormal" or pathological grief as distinct and mutually exclusive in relation to "normal" grief. For example, Freud (1917) felt that self-hate following bereavement would signal the presence of an abnormal grief process. Subsequent field studies revealed that a number of such pathological indicators were found among those grieving adaptively, leading to a blurring of diagnostic categories, and a general view of a typical-atypical continuum (Rees, 1975).

Currently, many theorists distinguish between the two categories simply in terms of duration and intensity of symptoms. More detailed formulations are also offered in the literature. For example, Lindemann (1944) observed that complicated grief appeared to resolve within a 4-6 week period, and that somatic distress, guilt, hostility, preoccupation with images of the deceased, and loss of patterns of conduct were pathognomic for grief. Volkan (1970) viewed pathologic grief reactions as a middle stage between normal grief and full-blown neurosis or psychosomatic conditions, and Bowlby (1980) noted that:

Clinical experience and a reading of the evidence leave little doubt of the truth of the main proposition --that much psychiatric illness is an expression of pathological mourning--or that such illness includes many cases of anxiety state, depressive illness, and hysteria, and also more than one kind of character disorder (p. 23).

Horowitz (1980), in discussing the Stress Response Syndrome, also commented on the construct of pathologic

grief:

The intensification of grief to the level where the person is overwhelmed, resorts to maladaptive behavior, or remains interminably in the state of grief without progression of the mourning process towards completion....[It] involves processes that do not progress towards assimilation or accommodation but, instead, lead to stereotyped repetitions or extensive interruptions of healing (p. 1157).

The most extensive statement regarding pathological grief is Parkes' (1965) classification of bereavement reactions summarized as follows:

A) Stress-Specific Reactions - grief and its variants

- 1) typical grief
- 2) chronic grief
- 3) inhibited grief (including absence of grief)
- 4) delayed grief

B) Non-Specific and Mixed Reactions - any of the above, plus:

- 1) psychosomatic reactions
- 2) psychoneurotic reactions
- 3) affective disorders not resembling grief
- 4) other conditions (p. 14).

Lastly, Worden (1982) has developed a taxonomy of diagnostic clues to aid the clinician in diagnosing pathological or complicated grief. These are:

- 1) inability to discuss the deceased without experiencing intense and fresh grief;
- 2) intense grief reaction triggered by a relatively

minor event;

- 3) themes of loss during the clinical interview;
- 4) person who has sustained the loss preserves the environment of the deceased and is unwilling to move material possessions belonging to the deceased;
- 5) physical symptoms like those of the deceased prior to death;
- 6) radical life changes in lifestyle;
- 7) history of sub-clinical depression or false euphoria;
- 8) compulsion to imitate the dead person;
- 9) self-destructive impulses;
- 10) unaccountable sadness at specific times during the year;
- 11) hypochondriacal phobias;
- 12) avoidance of mourning rituals or visiting gravesite.

BEREAVEMENT, GRIEF and MOURNING FOLLOWINGSUDDEN INFANT DEATH

While the death of a baby due to SIDS evokes grief and mourning as in other forms of bereavement, certainly this kind of trauma imposes special stresses on the survivors. First, the death of an infant in the twentieth century, unlike previous generations, is contrary to life cycle expectations. In addition, the cause of death remains a medical mystery despite advanced technologic and scientific achievements. These factors may combine to intensify the feeling of victimization. Also, the sudden, unanticipated nature of the death is considered to produce more distress than expected bereavements (Epperson, 1977; Lehrman, 1956; Levinson, 1972). The majority of SIDS parents are under 25 years (1/3 adolescents) and may be encountering death for the first time with the loss of their infant (General Accounting Office, 1981). Several theorists regard the death of a child as the most severe kind of bereavement (Elliott, 1978; Furman, 1978; Helmrath and Steinitz, 1978) and at least one empirical study supports this position (Sanders, 1980).

Several authors, discussing SIDS from a program planning and policy perspective noted a tendency to underestimate mental health problems among SIDS families

(Bergman, 1969; Goldston, 1976), and that families were considered to be at risk for psychiatric disorders, marital instability, and stress-related medical illness. Indeed, some of the reports note that SIDS bereavement precipitated suicide attempts and completions, as well as initial mental hospital admissions among previously well-functioning adults (Cain, 1977).

The study of grief and mourning in SIDS families appears to have progressed from the anecdotal and descriptive papers in the late 1960s and 1970s to more systematic and analytic studies, documenting the horror of death in infancy. Reactions of numbness and hysteria, accompanied by helplessness, anger, self-blame, hallucinations and suicidal ideation were consistently observed by physicians, nurses, social workers and others (Aadlen, 1980; Arnold and Ramsey, 1979; Blenninger, 1982; Bluglass and Hassall, 1979; Bluglass, 1980; Cain, 1977; Davis, 1975; Emery, 1972; Friedman, 1974; Goldston, 1976; Hawkins, 1980; Krein, 1979; Limerick, 1978; McElroy, et al., 1979; Merritt, et al., 1975; Miles, 1980; National Health and Medical Research Council, 1978; Patterson and Pomeroy, 1974; Pomeroy, 1969; Schodt, 1982; Szybist, 1976).

Later papers included the reactions of siblings, grandparents and other family members, and based on this

accumulated data, health and mental health professionals began to publish general strategies for helping the SIDS-bereaved. Important examples of this literature are presented below.

The most extensive study of the familial response is Smialek's (1978) unstructured interview with over 350 SIDS families at the office of the Medical Examiner in Detroit (at the time of identification of the deceased). She describes a consistent picture of shock, disbelief and denial of the tragedy mixed with negativism, hostility, self-reproach and guilt. Many parents expressed premonitions of the infant's death and connected the loss to previously unresolved guilt.

Another series of unstructured interviews with seventeen Australian SIDS families focused on the long-term response of parents, siblings and grandparents. On self-report, mothers averaged ten months and fathers three-and-a-half months to resume normal functioning. Marital discord was frequently observed (no pre-test or control group available) with the interviewer estimating that one-third of the couples would benefit from counseling. Paternal grief was less intense and fathers often maintained a protective role towards other family members. As late as thirteen months after the infant's death, mothers thought and dreamt about the baby twice as often

as the fathers. Tantrum and oppositional behavior was seen in toddler siblings, and children under age twelve evidenced anxiety, fear and sleep disturbances (Cornwell, et al., 1977).

A similar study focused exclusively on paternal grief evaluated by public health nurses during home visits (Mandell and Wolfe, 1980). Trends for the twenty-eight fathers interviewed included: intellectualized grief, remorse over lack of involvement with the baby, lowered self-esteem, feelings of helplessness and frustrations, and a perceived threat to one's manhood. Socially, many of the fathers adopted a managerial role--making funeral arrangements, supporting the wife's distress, and controlling their own emotions. Often they became very involved in work and out-of-house activities. Two other significant observations were that not one father interviewed was hesitant about having a subsequent child and that nearly forty percent of the original survey sample declined the home visit by the nurse.

The effects of SIDS bereavement on subsequent pregnancy was examined by Mandell and Wolfe (1975), by reviewing the health record of forty-one previous SIDS mothers. The authors found higher rates of fertility problems and spontaneous abortions among this select group in comparison to the general population.

Lovett and Gold (1977) interviewed fifteen sets of bereaved parents less than six months after the SIDS event and found a negative correlation between degree of grief resolution and ambivalence among fathers, a positive association between socioeconomic status and grief resolution for both parents, and a positive association between grief resolution with having subsequent children.

A thirteen-page questionnaire was sent by mail to all SIDS families in Nebraska during the period 1973-5, with a return from 32 respondents (approximately a two-thirds return). The authors found that it took an average of six to nine months for family functioning and household routines to resume fully, and, on average, 15.9 months for the parent to achieve a level of personal happiness similar to the pre-loss period. Nearly seventy percent of the respondents reported severe guilt feelings, and recovery time was not related to prior knowledge of SIDS, performance of an autopsy, church affiliations or number of personal friendships (DeFraain and Ernst, 1978).

While these kinds of articles and presentations have continued in the SIDS literature and at bereavement conferences to the present date, the early 1980s marked the first controlled study of SIDS mothers and since

then a growing number of systematic efforts have become available.

Rubin's (1981) doctoral dissertation was the first SIDS study to employ a control group as well as multiple instruments. Using several personality scales and a measure of grief administered via a semi-structured interview, the author compared three groups of married women, matched on a variety of demographics including previous psychopathology. Recent SIDS mothers (3-10 months past the death) were characterized as having a negative view of the environment and overall impaired functioning as compared with distant SIDS mothers (2-6 years past the death). Despite the observations that affective involvement with the lost infant continued for as long as four-and-a-half years, the distant SIDS mothers were generally indistinguishable from a non-bereaved control group. In a later retrospective qualitative analysis, Rubin (1985), observed the long-term persistence of guilt despite decreases in anxiety, depression, hostility and helplessness.

A variety of retrospective mail surveys were conducted further detailing the grief and mourning reaction. Crichton (1983) observed the typical grief responses and marked social support for 241 British families. Williams and Nikolaisen (1983) assessed coping patterns in seventeen

couples and 37 mothers and concluded that married or single SIDS mothers experience more intense emotional distress and are more expressive. Married parents and fathers in particular report more social support and appear more reconciled to the loss. Dyregrov and Matthiesen (1987a, 1987b) conducted two studies of bereaved parents. The first compared parental anxiety following stillbirth, neonatal loss and SIDS and indicated that SIDS parents showed the highest level of anxiety which was correlated with: (1) lack of social support, (2) younger aged mothers, and (3) mothers as opposed to fathers. The second paper assessed mother-father differences in grief, perception of support and psychological well-being, among couples who had experienced a stillbirth, neonatal loss or a SIDS. Mothers were found to experience higher levels of anxiety, depression, somatic distress and intrusive thoughts--all within the context of a slower recovery. Variations in mourning was also the theme of Nicholas and Lewin's (1986) comparison between couples grieving over their child's handicap and SIDS parents. The findings indicated higher anxiety, depression and grief for SIDS parents, with mothers, in general, being more depressed.

Burns (1986) used a mail questionnaire to survey parental views of sibling reactions to a SIDS and noted

that one year was the most frequently mentioned duration of sibling mourning. Using a panel design, Woodward et al. (1985), found that long-term use of counseling services among thirteen SIDS families was related to marital conflict and non-supportive extended family. Tudehope et al. (1984), used structured interviews (no control group) to investigate pathologic grief. They concluded that the severity of the initial grief response was predictive of later pathologic grief and that social support was negatively correlated with pathologic grief. Lewis (1983) compared 60 SIDS mothers with a non-bereaved control group and found no significant differences in trait anxiety, but greater state anxiety for the SIDS group at three months and fifteen months after the death. In addition, the researcher explored the effects of maternal anxiety on the emotional security of subsequent births and found no statistically significant differences. Pflaumer (1983) used a phenomenologic case history method with thirteen SIDS parents in order to assess factors associated with positive coping. Several important observations were reported: (1) self-blame appeared to be mitigated by social support, (2) marked apprehension of future losses, and (3) the salutary effects of an internal locus of control.

An unusual topic, the reactions of SIDS parents

and counselors to reading their child's autopsy report, was the subject of a non-controlled survey by Kotch and Cohen (1986). The authors concluded that this intervention was almost always viewed as valuable though parents evidenced a less-than-complete understanding of the information. A psychosocial literature reviewed by Bluglass (1981) was more a highlighting of issues than a compilation or synthesis. Finally, SIDS research began to evolve in yet another direction with two efforts to develop instrumentation. Aadlen's (1983) SIDS Parent Coping Inventory and May and Breme's (1983) SIDS Family Adjustment Scale have been the initial efforts in this area.

CRITICISMS AND ALTERNATE MODELS

The limitations of traditional crisis theory have been noted by many of its proponents, with Lukton's (1974) critique of its assumptions, concepts and paradigms being the most comprehensive.

A central issue appears to be the elusive definition of the "state of crisis", a construct at the very heart of crisis theory. Thus, if a person is not outwardly seriously disturbed following a traumatic incident, clinicians assume that the reaction is suppressed or repressed, and the excavation of this stress becomes a therapeutic focus. If there is genuinely no distress (which is prob-

ably not theoretically acceptable), the practitioner's efforts to unearth such reactions ("Why aren't you angry... you must be angry.") are clearly damaging to the client. On the other hand, if one presents with significant emotional turmoil without a precipitating external event, then the crisis state is attributed to internal difficulty. The latter explanation makes it difficult to disentangle the crisis entity from any form of psychosocial disorder.

The proposed duration of the state of crisis (4-6 weeks) has also been challenged repeatedly in the literature.

Lewis (1979) found that contrary to present notions, the duration of crisis for cancer patients was found to be greater than six weeks but less than seven months. Wikler et al. (1981), re-assessed the chronic sorrow attributed to parents of mentally retarded children and found that crisis theory did not account for the long-term periodic crises which the families faced. Finally, it is data regarding bereavement which most contradicts the 4-6 week postulated duration, and these findings will be presented shortly.

Lukton (1974) concludes that:

The concept of crisis as a universal human phenomenon lacks the capacity to be confirmed by unambiguous observational evidence...and should perhaps be regarded as an attractive metaphor rather than as theory subject to substantiation or negation on the basis of empirical evidence (p.385).

Overall criticisms of crisis theory include the following by some of its leading proponents:

Parad (1974) notes that "the constructs and techniques of the crisis approach lack the formal attributes of a systematically validated theory" (p.197). Rapoport (1970) concurs that:

It is not a well-formulated or holistic theory with systematically validated propositions...The parameters of crisis theory have not been spelled out...At best, it is a framework for viewing individuals and families in situations of urgency and stress (p. 102).

Similarly, Golan (1974) suggests that:

The parameters are too broad and amorphous to grant it recognition as a systematic theory, in the sense of being an internally consistent body of verified hypotheses (p. 420).

Overall, then, we can observe the theoretical and conceptual limitations of the crisis concept in general, and its applicability regarding the "crisis state", of bereavement in particular.

The extant literature in the areas of grief and mourning are similarly problematic.

The dominant psychodynamic position portrays grief paradoxically as a clinical syndrome/disease entity which is apparently essential in order for the individual to resume normal functioning, the absence of grief being regarded as a clear sign of emotional disturbance (Goldberg, 1973). Such grief may be regarded as atypical or abnormal

when it exceeds prescribed time limits, style and depth of expression. Moreover, the diagnostic determination of a pathologic grief state appears to incorporate almost every known form of psychopathology, and guidelines such as those proposed in the literature seem simplistic and non-specific in relation to bereavement (Worden, 1982).

The implications from these positions is that in any form, grief may need to be "treated" by professionals and, in fact, the field of bereavement counseling espouses such a view. One remains unsure as to whether normal grief, abnormal grief, neuroses, character and psychosomatic disorders, or psychoses, should be the focus of such intervention.

In contrast with the linear and medicalized descriptions of grieving presented earlier in this chapter, several cross-cultural studies confirm that the typical grief reaction is not a universal response to bereavement. The most extensive of these works is Rosenblatt's (1976) "Grief and Mourning in Cross-Cultural Perspectives", a survey of 78 societies around the world which highlights the many differences (and similarities) in the human response to loss.

In a study on bereavement among Samoans, Ablon (1971) writes:

Although Lindemann labelled the grief syndrome as pathognomic, this phenomena may well be

culturally linked to members of our own society with whom Lindemann worked. Interviews with Samoans suggest that the syndrome does not occur in this form among bereaved Samoans. Likewise, grief work appears to be rapidly and less painfully accomplished by Samoans because of ritualized family and community support, and cultural attitudes relating to death (p. 330).

Yamamoto (1969) observed a number of culturally-related departures from the norm in his study of Japanese mourners. Emphasizing the therapeutic importance of maintaining ties with deceased ancestors, he points out that:

In Tokyo, the process of mourning is different due to cultural beliefs. 90% of the widows worked to maintain ties with the deceased, who becomes an ancestor. This is of course the counterpart of the 21% of British widows who worked to cultivate the idea of the presence of the deceased. The important theoretical difference is that in Tokyo, this is acceptable and encouraged by the culture and religious ritual (p. 1664).

Miller and Schoenfeld (1967) focused on grief among Navajo Indians and offered that theorists such as Freud, Parkes and Clayton:

...do not take into account the culture of the mourner. It is our belief that the culture significantly affects the mourning process, and may either aid or interfere in the successful resolution of the process (p. 187).

The "stage" approach to grief and mourning has also been challenged by several writers:

Bugen (1977) finds five theoretical weaknesses and inconsistencies in the stage concepts of grieving:

- 1) stages are not separate entities, but tend to blur and overlap
- 2) stages are not successive
- 3) it is not necessary to experience every stage
- 4) intensity and duration of any one stage may vary idiosyncratically among those who grieve
- 5) little empirical evidence is offered by proponents of the approach.

Bowlby (1980) also notes that stages overlap and are seldom distinct, and Worden (1982) suggests that the stage approach is less clinically useful than other constructs, such as tasks. "Phases imply a certain passivity something which the mourner must pass through" (p.32), whereas tasks require active participation and are closer to Freud's concept of grief work.

Metzger's (1980) Q-methodological study of Kübler-Ross's theory found no evidence of stages in grieving, and Kastenbaum's (1975) evaluation of Kübler-Ross's pioneering work finds that:

The rapid acceptance of the stage theory...has quite outdistanced any attempt to examine the theory empirically or logically. It is taken typically as proven fact. Research may be viewed as superfluous (p. 42).

He further criticizes her data base and notes that there is no description of sample, definition of terms, analysis of transcripts, no interrater reliability or statistical

data. Kastenbaum (1975) further lists six factors insufficiently considered by the stage approach which are likely to influence the grief process:

- 1) nature of the disease
- 2) sex differences
- 3) ethnicity
- 4) personality or cognitive style
- 5) developmental level
- 6) sociophysical milieu

Kastenbaum (1975) concludes with the following caveat to practitioners:

Both the stage theory...and developmental theories in general sometimes fail to distinguish adequately between what usually happens and what should happen. Less a problem of the theory itself than of some of its applications, there is nevertheless a disturbing tendency for description to be converted imperceptibly into prescription (p. 45).

Early notions about the duration of the grief response (a dimension of normal vs. abnormal grieving) have similarly been scrutinized. In an investigation of the stages of bereavement, Hardt (1979) extended the mourning period to eight months.

In the Forward to a study of conjugal bereavement, Gerald Caplan (1974), the father of preventive psychiatry, writes:

First, it reveals our realization that Lindemann's early conceptualization of

bereavement as a typical life crisis was an oversimplification...We have learned that the forces of bereavement and adjustment usually operate over a much longer period of time, that is more appropriately labeled a 'period of life transition' than a 'life crisis'...The second main theoretical lesson has been an increased understanding of the 'normality' and benign predictive significance of many of the strange individual reactions (p. VII).

Finally, the comprehensive review of bereavement literature conducted by the Institute of Medicine (1984), extends "normal" grieving to years after the loss and raises some question as to whether this focus on parameters is clinically useful.

The traditional, linear, deterministic view of bereavement is, not surprisingly, associated with clinicians and researchers who were primarily physicians. The medicalization of grief by Freud, Lindemann, Bowlby, Parkes, Kübler-Ross and others reflects the disorder-specific and dose-response understanding of disease. Thus, each stress disease is associated with a particular stressor (grief → bereavement) and the greater the stress the more likelihood of disease.

An alternate view of bereavement would reject the disorder-specific, dose-response approach, as Cassel (1976) has observed:

There is serious doubt as to the utility or appropriateness of both of these notions... It is most unlikely that any given psychosocial process or stressor will be etiologically specific for any disease, at least as currently classified (p. 109).

Instead, a more systems-oriented approach is supported by Dubos' (1968) observation that even infectious diseases do not occur only, or even most frequently, from exposure and infiltration of a noxious agent (Bloom, 1979; Dubos, 1968). Rather, stressors disturb the balance between agents present in the environment and the host that is harboring or exposed to them. Psychosocial events and processes thereby influence wellbeing in two ways. As stressors, they upset the balance between various systems (individual-family, cognitive-endocrine, family-culture, etc.) producing stress and vulnerability to a range of dysfunctions, and as buffers they protect or cushion the individual from the physiological or psychological consequences of exposure to the stressor.

In terms of grief and mourning, bereavement would be regarded as a stressor and grief as the manifestation of stress accompanying a general vulnerability to a variety of biopsychosocial disorders (Blauner, 1966; Pollock, 1961; Schmidt, 1983). Pathological grief as a separate entity or disease state would be considered superfluous.

Another derivative of this approach is that the reaction to stressful life events such as death is less fixed or predictable than traditional crisis theory and grief theory propose. A wide range of systems forces in the person-environment matrix impact upon the perceived

and actual stressfulness of the precipitant as well as the nature of the stress response (Horowitz, 1976). Two important issues are the cognitive systems attribution process and the social network/support (the latter to be reviewed next chapter).

In terms of cognition and attribution, Epictetus observed that "men are moved not by things but by the views which they take of them," and "somewhat more recently", Lazarus (1980) and others have produced extensive empirical support for the mediating role of cognitive processes in psychological stress, and the developing field of cognitive therapy derives from this perspective.

In terms of bereavement, Bugen (1977, 1978) offers a two-factor cognitive model of grief which predicts the duration and intensity of response as a function of the bereaved person's sense of centrality (closeness) and preventability of the death. Yielding a 2 x 2 matrix his approach appears as follows:

Figure 1

| | CLOSE | NOT CLOSE |
|-----------------|-------------------|----------------|
| PREVENTABLE | Long and intense | Long and mild |
| NOT PREVENTABLE | Brief and intense | Brief and mild |

Sudden infant death syndrome is thus likely to produce an extended, intense grief reaction. In the absence of a definite cause of death and in the context of societal emphasis on parent responsibility, mothers, fathers, and other caretakers struggle with severe self-blame and guilt. Also, most parents would describe their relationship with their infants as central. However, the cognitive emphasis also allows for minimal or even absent grieving, not as a sign of psychopathology, but simply as a reflection of a lack of perceived preventability or centrality. Persons who steadfastly attribute the infant's death to Divine Will, SIDS, or any other external, non-preventable source would be expected to grieve for a shorter period of time. Similarly, mothers and fathers who did not feel a sense of closeness with the baby, or those for whom the infant was associated with some kind of negativism would be expected to show a mild or minimal grief response. Parental disaffection or rejection is commonly encountered in life relationships and its presence in the midst of bereavement need not readily be attributed to psychiatric disorder.

APPLICATION CONCEPTS DERIVED FROM THE LITERATURE REVIEW

In accord with the Social R & D model, generalizations and application concepts are noted for each section of the review.

BEREAVEMENT, GRIEF and MOURNING

1. The grief response is not a disease entity which needs to be diagnosed as pathological, delayed, distorted, etc., rather, it is a part of a stress situation, which is superimposed over the individual or family's current functioning, at times exacerbating chronic, extant problems. Bereavement and its attendant grief, produces a general vulnerability to physical, psychological and social dysfunction.
2. The grief response following bereavement is not a fixed, predictable process, but is rather multi-determined, and in some instances may not be present. The intensity and duration of the distress varies with the culture, religion, social network, cognitive and emotional nature of the mourner.
3. Primary prevention is not aimed at the grief response itself, or even at what is called "pathological grief" by some theorists. Rather, the bereavement produces a general vulnerability to stress-related disorders, and it is these which we attempt to mitigate.

4. Stress-related problems and maladaptive grief reactions are more likely among the "high-risk" bereaved, making this group more suitable for preventive and early intervention.
5. SIDS bereavement is a stressful life event and social status, which for a variety of reasons, may be regarded as more potentially disturbing than other kinds of bereavement.

COPING: PERSON-IN-ENVIRONMENT

Definitions and Typologies - It has been said that we now call "coping" what was once referred to as "living", and indeed an operational definition of the phenomenon is not easy to come by.

White (1974) reviewed the concepts of adaptation, mastery, coping and defense, noting that adaptation is the master concept under which the other terms assume a more restricted meaning. Defense, clearly rooted in psychoanalytic theory, is best used in instances which present danger and anxiety to the individual, while mastery is suitable to problems with a cognitive or manipulative complexity. Coping is used most often in situations requiring drastic change, often accompanied by emotional distress. "Coping refers to adaptation under relatively difficult conditions" (White, 1974, p. 49). Interestingly, Mechanic (1978) notes that defense mechanisms when divorced from coping are usually viewed as emotional disturbances.

In their analysis of the structure of coping, Pearlin and Schooler (1978) offer the following definition:

By coping we refer to the things that people do to avoid being harmed by life strains. At the very heart of this concept is the fundamental assumption that people are actively responsive to forces that impinge upon them... Essentially the concept is being used here to refer to any response to external life strains that serves to prevent, avoid, or control emotional distress (p. 2).

They also offer an important distinction between social resources, psychological resources, and specific coping responses. Social resources are found at various systems levels ranging from the societal to the familial. The social networks which people are a part of play a crucial role in providing social support and stress buffers. Psychological resources represent some of the things that people are, the personality characteristics brought to a variety of roles. Lastly, coping responses are specific behaviors, cognitions and perceptions which people employ to contend with stress.

Several researchers and clinicians have attempted to identify these key coping processes.

White (1974) focused on information, internal organization and autonomy. Securing adequate information about the environment is a basic component since activities will be most successful if there isn't a deficit or overload of information. A second process is the maintenance of a balanced internal organization which is often affected by cognitive and emotional processes. Autonomy requires that freedom of action be available, especially escape routes. These three factors operate within a time dimension which acknowledges that coping strategies are not created instantly, but rather evolve and are progressively modified over time.

Pearlin and Schooler (1978) also designated three key coping processes: responses that change the situation, responses that control the meaning of the situation before the emergence of stress, and responses that attempt to control stress. Responses that directly modify the situation are aimed at altering or eliminating the sources of strain. The stressful impact of a problem may be buffered by responses that function to control the meaning of the event. One such mechanism involves making positive comparisons in relation to previous distress or the distress of others. Another device is selective ignoring which is accomplished by locating some positive attribute or circumstance within a disturbing situation. The third type of coping endeavors to manage stress rather than to prevent it, and thereby helps people adapt to stress rather than be overwhelmed by it. Often cultural beliefs, values and folksayings attempt to promote endurance and forbearance. In fact, there would appear to be a wide range of responses that may be used to manage stress but are otherwise routine activities.

Mechanic (1978) identifies five intervening variables essential to the perception of and response to life crises:

- 1) material resources - largely economic
- 2) appropriate skills - coping repertoire
- 3) adequate defenses - cultural and personal devices that enable the person to contain and control emotional distress
- 4) social supports - tangible and symbolic assistance via one's social network
- 5) sustained motivation - successful coping depends

on continuing willingness to remain engaged in social intercourse. Continuing involvement in tasks and relationships maintains psychological identity and social roles.

On the familial level, McCubbin (1980), in his decade review (1970s) of family stress and coping, focused on Hill's ABC-X model in terms of more recent theoretical and empirical findings. He observed that coping research in the family field has been dominated by cognitive-psychological and some sociological theories, as evident in the items below. Coping behavior consists of managing various aspects of family life simultaneously:

- 1) maintaining satisfactory internal conditions for communication and family organization
- 2) promoting member independence and self-esteem
- 3) maintenance of family bonds of coherence and unity
- 4) maintenance and development of social supports in transactions with the community
- 5) maintenance of some efforts to control the impact of the stressor and the amount of change in the family unit.

He concluded that:

Coping is thus a process of achieving a balance in the family system which facilitates organization and unity, and promotes individual growth and development (McCubbin, 1980, p. 865).

McCubbin (1980) noted that perception of an event/situation has become the key factor in the study of normative and non-normative stresses. Thus, unlike the individual in crisis:

When the family system is the unit of analysis,

perception as a variable is enigmatic, as the source of perception is often unclear (p.862).

The reviewer is left to ponder, "Is there a collective family perception?"

Reiss and Oliveri (1980) respond that there is, and this family process is at the heart of its adaptive capacity and response. They proposed the concept of a family paradigm which directly shapes coping with stressful events and circumstances. The paradigm consists of shared beliefs, assumptions and orientations concerning the social environment. The problem-solving behavior exhibited by the family varies along three dimensions: configuration, coordination, and closure. Configuration is the family's belief that their social world is ordered by a logical set of principles which can be discovered and mastered via exploration and interpretation. Coordination is the dovetailing of problem-solving efforts with other family members. Closure is the degree to which families delay decision-making until they have all the evidence they can obtain.

Coping has also been conceptualized in terms of "tasks" which consist of affective, cognitive, behavioral and social processes deemed necessary to insure an adaptive outcome following stressful life events and transitions (Bartlett, 1970). The early crisis intervention studies identified coping tasks for situational crises such as

bereavement (Lindemann, 1944) and birth of a premature child (Kaplan & Mason, 1960) and for maturational crises such as becoming engaged (Rapoport, 1963). After a period of general crisis formulation, the field appears to be moving again in the direction of developing tasks for specific life crises (Aguilera & Messick, 1978; Burgess & Baldwin, 1981; Smith, 1978).

The coping tasks specified for bereavement are summarized by Worden (1982):

1. to accept the reality of loss, including the meaning and irreversibility of loss;
2. to experience the pain of grief;
3. to adjust to an environment in which the deceased is missing;
4. to withdraw emotional energy and to reinvest it in another relationship.

Goldberg (1973) has delineated the family coping tasks following death of a member:

1. allowing mourning to occur
2. relinquishing the memory of the deceased
3. realignment of intrafamilial roles
4. realignment of extrafamilial roles

Criticisms and Alternate Models - The coping and adaptation literature is dominated by the position that the outcome of such efforts depends largely on skills,

defenses, motivation and similar individual/familial components (Coelho et al., 1974). As Morley (1980) notes:

If the person had a repertoire of coping mechanisms adequate to deal with the life stress, he or she would not have gone into crisis in the first place (p. 18).

This perspective clearly emphasizes the "person" within person-environment and the focus of professional intervention is similarly established. Little acknowledgment is given to the role of the environment--the economy, sociopolitical situation, societal ideologies, religious beliefs and cultural institutions--as a force which both produces stress as well as the range of possible coping solutions. Mechanic (1974) writes about this neglected dimension:

Man's ability to cope with the environment depends on the efficacy of the solutions that his culture provides, and the skills he develops are dependent on the adequacy of the preparatory institutions to which he has been exposed (p. 33).

Many of the coping formulations emphasize the destructive potential of defense mechanisms and coping strategies which deny or distort external reality. Clinicians appear to acknowledge the need for denial as a protective device, but there appear to be few guidelines for distinguishing adaptive from maladaptive forms. Yet, there are other perspectives on the relationship between effective coping and perception of reality. Mechanic (1974) raises the issue of adaptive denial:

It is incorrect to assume that successful adaptation requires an adequate perception of reality...Many misperceptions of reality aid coping and mastery, energize involvement and participation in life endeavors, and alleviate pain and discomfort that would detract the person from successful efforts at mastery. Reality, of course, is a social construction, and to the extent that perspectives are shared and socially reinforced, they may facilitate adaptation irrespective of their objective truth. It is well known that if men define situations as real, they are real in their consequences (p. 38).

On the other hand, those who embrace a painful reality too quickly are equally suspect, as Lazarus (1980) notes:

Contrary to common-sense viewpoint, clinicians assume that the person who seems to think positively is actually involved in self-deception, using denial or reaction formation as a defense and thereby concealing conflicting inner states (p. 92).

As noted earlier, the helping professions have adopted a view of coping which emphasizes the competence and resources of the individual or family. However, social work's historical commitment to addressing both person and environment requires a broader, transactional focus on coping and adaptation (Anderson and Carter, 1974). Ecological and systems theories facilitate this kind of perspective by considering the numerous forces and influences which affect and, in turn, are affected by the individual or family (American Psychiatric Association, 1979). Concepts regarding the social environment, social stress and support and networks broaden and enrich the

existing coping paradigms, and these areas will be reviewed.

Insel and Moos (1974) offer the following observations about social environments:

Like people, environments have unique personalities. Just as it is possible to characterize a person's personality, environments can be similarly portrayed with a great deal of accuracy and detail. Some people are supportive, likewise some environments are supportive. Some men feel the need to control others; similarly some environments are extremely controlling. Order and structure are important to many people; correspondingly many environments emphasize regularity, system, and order (p. 56).

Insel and Moos (1974) have conceptualized human environments in terms of social ecology, organizational structure, personal characteristics of milieu inhabitants, behavior settings, and functional or reinforcement properties of environments, and have developed "perceived climate" scales to measure a variety of specific environments. The common features of the many environments studied are:

- 1) relationship dimensions - nature, intensity and supportiveness of personal relationships within the environment
- 2) personal development - potential or opportunity in the environment for growth and development of self-esteem
- 3) system maintenance - extent to which the environment is orderly and clear in its expectations, maintains control and is responsive to change.

The social environment serves as the context in which social stress and social support occur.

Environmental or social stress, in the form of chronic adverse living conditions or stressful life events and transitions, has been implicated in a plethora of human maladies (Brown, 1980; Dohrenwend & Dohrenwend, 1980; Kessler, 1979). However, the environment is also believed to contain stress-buffering elements primarily in the form of social support (Dean and Lin, 1977).

Several definitions of this vital concept have been proposed:

Lin et al., (1979), viewed the phenomenon as:

Support accessible to an individual through social ties to other individuals, groups and the larger community (p. 109).

Pilisuk (1982) noted that:

Social support refers to those relationships among people that provide not only material help but also the sense that one is a continuing object of concern on the part of other people (p. 20).

Cobb (1976) regarded social support in terms of information which may be categorized in the following way:

- 1) information that causes the person to feel loved and cared for;
- 2) information that causes the person to perceive himself as belonging to a social group.

Using a communications perspective, Albrecht and Adelman (1987) observed:

Social support refers to verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life experience (p. 3).

Social support may be sporadic and random or it may become a regular component of the environment in the form of support systems at various societal levels. Such a system:

...implies an enduring pattern of continuous or intermittent ties that play a significant part in maintaining the psychological and physical integrity of the individual over time (Caplan, 1976, p. 20).

The lack of social support, along with social marginality, adverse social status, and disturbed/disrupted interpersonal relations, appears to be consistently related to higher risks of physical, psychological and social disorders. Social marginality is associated with persons who develop tuberculosis, hypertension, schizophrenia, alcoholism and frequently characterizes victims of suicide, multiple accidents and persons admitted to psychiatric hospitals in general. One review of the literature hypothesized marginal social status as a major factor accounting for the higher mortality rates, from all causes among the poor (Pilisuk, 1982).

Significant epidemiologic evidence comes from several doctoral dissertations from the School of Public Health, University of California (Berkeley). Froland, et al., (1979), demonstrated that degree and type of social

integration was clearly related to severity of psychological and behavioral disorder. A major cross-cultural study found coronary disease to be highest among Japanese men living in California, lower among those residing in Hawaii, and lowest among those at home, in Japan. Controlling for such commonly associated risk factors as smoking, obesity, serum cholesterol and diet, the researchers attributed the higher rates of disease to increasing dissimilarities with traditional Japanese life styles (Marmot and Syme, 1976).

Another significant longitudinal study showed that disease morbidity and mortality rates from all causes among the residents of Alameda County, California, were related to an index of the individual's interpersonal connections at the beginning of the study, regardless of sex, ethnicity or socioeconomic status (Berkman and Syme, 1979).

In addition, numerous laboratory studies regarding hypertension in mice, neoplasms in chickens, experimental neurosis in young goats, as well as the classic Harlow and Bowlby research, further support the significance of social ties in the reduction or prevention of disease and dysfunction. Pilisuk (1982) responds to critics, when he writes:

Serious questions have been raised regarding the direct extrapolation of such experimental

findings, mostly with animals, to conclusions about sociopsychological factors in human health. It is the apparent convergence, however, of so diverse a set of experimental and epidemiological findings that makes so compelling a case for the effects upon health of predictable and familiar social support (p. 20).

A striking piece of evidence comes from a study by Nuckolls, Cassel and Kaplan (1972), which focused on the relationship between life stresses, perceived social support and pregnancy outcome. The authors concluded that neither life stress scores nor perceived social support alone were significantly related to complications of pregnancy. However, those mothers with high stress scores both before and during pregnancy and perceived low social support were three times more likely to have pregnancy complications than similarly stressed mothers who perceived high social support. Since pregnancy is a health change which challenges the adaptive capacity physiologically, psychologically and socially, the impact of stress and social support is of particular significance.

Although the available data consistently reveals the positive effects of social support, the actual mechanism by which it serves a protective, stress-reducing role is less understood. Presumably social support influences the individual's immune system, a complex of factors related to the activities of antibodies, metabolic

and endocrine responses and psychological mechanisms which function to reduce disruptive levels of distress.

Stressor events which began as symbols (concepts, ideas, and perceptions) are accompanied by distressing emotions which disturb the regulating activities of the hypothalamus, autonomic nervous system, the reticular formation, and the pituitary and adrenal glands. When such stress reactions are significantly powerful and prolonged, they are likely to form the basis of the psychosomatic portion of most illness, and the intensity and duration of such responses appear to be directly mediated by a variety of cognitive processes. As noted earlier, the coping and adaptation literature offers several typologies of these processes.

Pilisuk (1982) reaches the following conclusion.

It is probably through the important role of other people as predictable abetments to one's self-esteem and powers of coping,, that social supports affect our restorative, physiological and psychological capacities, and ultimately the various immune systems of the body...It is in this way that basic symbols of each individual's life may be reaffirmed and protected by the presence of an enduring set of significant others (p. 25).

The salutary effects of social support become available to the individual or family in the context of their social network, the actual or potential subjective community of persons, groups, and parts of formal organizations/institutions. Whereas social support systems usually

refer to formally organized entities (families, neighborhood, church, etc.), social networks are the salient reference group of the individual or family, one's personal network.

In their analysis of the effects and determinants of social networks, Mitchell and Trickett (1980) reviewed a variety of criteria for network membership. These are based on whether all members are listed, as well as the degree of frequency of contact required for inclusion. The characteristics of social networks consist of structural features (properties of the overall network).

Structural characteristics include: size, range, density segmentation, reachability, and degree of connection. Linkage characteristics include: intensity, durability, multidimensionality, directedness and reciprocity, relationship density, dispersion, frequency and homogeneity.

Several writers have focused on the functions served by social networks.

Brim (1974) lists: concern, assistance, similarity of values, trust, and desired interaction, whereas Tolsdorf (1978) focuses simply on support, advice and feedback. Walker (1977) emphasizes five features: emotional support, material aid and services, maintenance of a social identity, diverse information, and access to new social contacts.

Weiss's (1974) functions include: attachment, exchange of services, guidance, social integration, sense of alliance, reassurance of worth and the opportunity to provide nurturance.

Unger and Powell (1980) indicated that social networks provide essentially three types of aid:

- 1) instrumental support in the forms of material goods and services to alleviate financial and economic situations;
- 2) emotional support which communicates to the family member that he or she is loved, esteemed and mutually obligated;
- 3) referral and information regarding other sources of help within and outside the family's network.

Lastly, Caplan (1976) designates emotional support, task-oriented assistance, communication of evaluation and expectation, and sense of belonging.

It has also been hypothesized that social networks can influence help-seeking in four ways:

- 1) by buffering stress and obviating the need for help;
- 2) by providing instrumental and affective support and thereby precluding the need for professional assistance;
- 3) by acting as screening and referral agents to professional helpers;

- 4) by transmitting attitudes, values and norms about help-seeking.

Pattison (1975) has formulated a typography of the personal social network by dividing it into three sectors: kinship, friendship, and caregivers. The latter will be reviewed under the INTERVENTION section.

1. Kinship - For most individuals, by all accounts, the kinship sector consisting of the nuclear and extended family and blood relatives is the primary support system, and Caplan (1974) has described the supportive functions of the family as follows:

- 1) collector and disseminator of information about the world
- 2) feedback guidance system
- 3) source of ideology
- 4) guide and mediator in problem-solving
- 5) source of practical service and concrete aid
- 6) haven for rest and recuperation
- 7) reference and control group
- 8) source and validator of identity
- 9) contribution to emotional mastery.

Unger and Powell (1980) emphasized that a "closed system" view assumes that a family's ability to cope with crisis and stress is based largely on the attributes of that family and its members, and that researchers

and clinicians have focused heavily on family structure and family dynamics. They propose, instead, an "open system" approach which acknowledges the family's embeddedness in its social environment. We thus maintain a dual unit of attention, the individual within his social network and the family within its social network.

It is also significant to note, that contrary to popular belief, the extended family "is alive and well" as a form of social support (Sussman and Burchinal, 1962).

2. Friendship - The friendship sector includes friends, neighbors, workmates and other associates, and in some areas may overlap with the caregiving sector.

3. Caregivers - The caregiver section may include "natural helpers", mutual aid and self-help organizations, professionally trained helpers and social agencies and institutions. A useful distinction may be made between natural helpers such as family and friends, and "artificial" providers which are brought into the situation when existing supports and resources are inadequate.

Social support and social networks are the key elements in focusing on the environmental aspects of coping and adaptation. However, even cognitive components may be viewed in terms of their social dimensions. For example, Mechanic (1974) identified how three cognitive coping processes interact with the social environment.

The search for meaning, which accompanies life crises, may be somewhat conditioned by the mass media or informal learning, as people may substitute "packaged responses" instead of the usual search to understand what might be occurring. In addition;

The less a particular crisis is shared by others, the more uncertain and problematic the response...The process through which crises may alternatively be defined as 'personal' or as a result of 'social problems' is particularly important, since the latter definition helps maintain the person's self-esteem and provides many new opportunities to cope with distress more actively (Mechanic, 1978, p. 300).

Attribution enables the individual to determine the relative role of external vs. internal causes in shaping the event and one's feelings about it. External attribution of failure and misfortune may mitigate personal blame and distress and the social dimension of this suggests that:

The ease of making attributions to external causes to explain one's problems depends on the availability of consensual validation, perhaps by subgroups (p. 302).

Social comparison is clearly rooted in the social environment and persons may evaluate their competence, obtain cues regarding the meaning of events, and review appropriate coping strategies through this process.

Social comparison may be a source of values, a means to evaluate one's adaptive responses and a mode of measuring progress (p. 303).

As with the other aspects of coping, the role of the environment in relation to the coping tasks appears to be minimal or virtually absent in the literature, with the emphasis still on the responses and resources of the individual or family. Yet, an alternate approach would view coping tasks as culturally embedded and consensually validated solutions to distress. This may help to explain differential coping in terms of one's cultural affiliation and the suitability of the prescribed tasks.

COPING AND SUDDEN INFANT DEATH

What are the implications of the data presented about coping and social support regarding the crisis of SIDS bereavement?

Some of the empirical and clinical findings suggest that persons with previous or current psychosocial disorders are more likely to fare badly as they pass through grief and mourning. Such disorders, whether described as known psychiatric syndromes or problematic social statuses, are stressors which increase vulnerability to a wide range of dysfunctional outcomes. A second, and perhaps more powerful, predictor of bereavement-related disturbance would be the actual or perceived lack of social support. Apart from the extensive epidemiologic and experimental evidence reviewed previously, several bereavement studies validate this position. Walker, et al., (1977), emphasizes the importance of social support networks following death of a spouse and Helmrath and Steinitz (1978) related the intense and prolonged grief of bereaved parents to a failure of social support. Raphael (1977) devised predictive indices of risk associated with conjugal bereavement focusing on perceived non-supportiveness among the widow's social network, and also found the lack of social support to be a risk factor among grieving relatives following a major train disaster in Australia. Finally, Polak, et al., (1975), tested the hypothesis that preventive crisis intervention

would decrease the risk of physical and psychosocial disorders among bereaved families following sudden, unexpected death. Observed differences between bereaved and non-bereaved controls appeared related to social support and individual factors but not to professional treatment.

Thus, one can observe that differential coping as reported in empirical data is probably due to a number of factors and that the presence or absence of previous or concurrent stresses and actual or perceived social support can identify those persons at greater risk for dysfunctional outcomes following a crib death.

The coping tasks for SIDS bereavement were derived both from the theoretical/empirical data regarding successful adaptation, as well as clinical experience with several hundred bereaved families. They are:

- 1) Attribution - All of the coping schemas reviewed previously acknowledged the significance of meaning and attribution in defining the impact of the stressful event, and this dimension assumes even more importance in relation to crib death. Since SIDS offers no explanation for the infant's sudden death, those responsible for the child's well-being will be more likely to blame themselves or in turn, be blamed by others. Although one researcher found that self-blame was positively corre-

lated with poor coping among accident victims, avoidability (preventability) was negatively correlated. The authors interpret the relationship between victimization, self-blame, and coping as reflecting the individual's need to perceive an orderly and meaningful world (Bulman and Wortman, 1977). This interesting finding has only limited applicability to SIDS in that self-blame implies having caused, through negligence, the death of one's child, not simply adult carelessness resulting in self-injury. While self-blame for SIDS parents conceivably makes the event less random, it is nonetheless psychologically intolerable. Rather, attribution for SIDS, given societal role definitions of parenting, revolves around the issue of preventability. Being responsible for the infant's life predisposes parents to internal attributions in response to SIDS, in three distressing ways: blaming oneself, being blamed by others, and blaming others (care-takers, emergency personnel), which still engenders a feeling of responsibility.

External attribution in SIDS acknowledges a lack of control (preventability) in relation to the infant's death. The explanation of the medical syndrome or designating the death as Divine Will or any similar lack of control/responsibility position serves as a cognitive antidote to self-blame and may help to suppress emotional

anguish and turmoil.

2) Maintenance of Role Performance - Role functioning is a transactional, systems concept connecting person and environment and reflective of an individual's psychosocial adjustment and overall mental health (Perlman, 1968). Role theory may be particularly useful in studying bereavement due to its cultural sensitivity regarding role expectations and enactment. In addition, recovery from an intense emotional experience may be more easily anchored in behavioral and attitudinal dimensions.

As part of a broad program of family research, Nye (1976) explored the variety of family roles, as well as empirical findings relating role competence to marital and parental satisfaction. He delineates the following:

- 1) Socialization and Child Care Roles - which overlap but are also conceptually distinct
- 2) Kinship Role
- 3) Provider and Housekeeper Roles
- 4) Sexual Role
- 5) Therapeutic Role
- 6) Recreational Role

The roles that SIDS parents need to maintain and/or recover would include:

- 1) Socialization and Child Care Roles - if there are other children in the family. Often the needs of

siblings are emphasized by relatives and others as a means of mobilizing the bereaved parent.

2) Provider and Housekeeper Roles - which may be allocated in a two-parent family or carried by a single parent. Provider roles include parents who are employed, as well as those who secure financial and material support through other means.

3) Kinship Role - beginning with the parental relationship (whether married or not) and extending to the other significant kin relations such as brother, sister, uncle, aunt, etc.

4) Friendship Role - which includes the recreational and therapeutic aspects reviewed by Nye. Given the young age of most SIDS parents and the increasing mobility of families, friendships are a major aspect of one's social network and hence a vital role.

5) Student Role - SIDS bereavement may occur while school attendance is a major aspect of a person's functioning. Ranging from bereaved teenagers in high school to young adults in advanced professional training, resumption of effective academic or vocational performance is necessary.

6) Mourner's Role - since most cultures have prescribed roles and rituals in response to bereavement and these are most likely mediated by one's social network/reference group, the failure to perform aspects of the expected

mourner's role may be regarded as dysfunctional and compromising of one's social support.

3) Regulation of Stress - an extension and combination of the regulation of information and the maintenance of internal conditions for processing data, the regulation of internal and external stressors is necessary to prevent overload or conversely entropy. Lindy, et al., (1981), described a crisis intervention program with survivors of the devastating fire at the Beverly Hills Supper Club in 1977. In assessing the recovery environment, the authors discovered a phenomenon which they labeled the "trauma membrane":

Severely traumatized individuals were often found to be surrounded by a small network of trusted people or an individual--spouse, older children, parents, a special friend or professional. These people serve to protect and buffer the survivor from perceived further external psychic stress, and attended to and monitored their needs. Those who functioned at this membrane tended to define for the survivor what was helpful and what constituted further trauma. Like its intrapsychic counterpart--the stimulus barrier--the trauma membrane protects at the psychosocial level an injured self from overload of psychic tension (p. 475).

Since sources of stress range from the societal to the intrapsychic to the endocrinologic, this last coping task is the broadest and most inclusive, since disturbing attributions and role strain or failure are also stressors.

There are two other dimensions in this alternate view of coping and adaptation. First, the coping tasks are viewed in a person-environment context, not simply as properties or responsibilities of the individual or family. Attribution, role performance and stress are influenced by numerous systems variables ranging from cultural and religious views to cognitive style and endocrine reactivity. In addition, the achievement of the coping tasks depends on the interaction of the individual/family with its social network environment. External attribution of SIDS may be facilitated or impeded by religious beliefs or blaming relatives; maintaining/recovery of parenting, spouse or worker roles will depend on the cooperation and assistance of role partners and network members; and the regulation of affective, cognitive, familial and social sources of stress draws on a plethora of coping/helping strategies and resources.

Second, this approach clarifies the meaning and application of the concept of support in coping and the human services. Support and supportive treatment have permeated social work theory and practice for over thirty years (Selby, 1979) and recently various kinds of support have been described as a necessary condition for change (Nelson, 1980). There is a basic question of what to support, and traditional crisis and coping theory answer

this in vague or universalistic terms. An alternate view would suggest that adaptive or interventive strategies be supportive of the particular coping tasks. Task-oriented support enables the focus to remain both on the person/family and the social environment. Thus, cultural attitudes, agency policies, family relationships and intrapsychic dynamics, to name but a few, need to be assessed and addressed in relation to their supportiveness of the designated tasks.

Coping, adaptation, and social support are the context in which professional intervention occurs, and this will be the focus of the next section.

APPLICATION CONCEPTS DERIVED FROM THE LITERATURE REVIEWCOPING: PERSON-IN-ENVIRONMENT

6. Coping with the stress of bereavement occurs naturally within individuals, families and their social networks. Self-help groups and a variety of professionals may be viewed as other sources of social support.
7. Coping with the stress of bereavement is affected by societal values, circumstances of the stressful life event, institutional policy and providers, the culture, religion, class, and social network of the mourner, as well as family dynamics, cognitive perceptions, problem-solving skills, etc.
8. The problematic experience of some families suggests that characteristics of the family and/or social environment may be assessed to predict greater or lesser risk of dysfunctional outcomes.
9. Coping with the stress of bereavement due to Sudden Infant Death Syndrome revolves around the three basic tasks: attribution, attribution to mitigate blame, role performance maintenance/resumption of essential roles (parent, spouse, worker, friend, student, etc.), and regulation of stress (prevention of lack of stimulation and tension overload during restorative period).

CRISIS INTERVENTION, BEREAVEMENT COUNSELING
& SOCIAL NETWORKING

CRISIS INTERVENTION AND BEREAVEMENT COUNSELING

The history of crisis intervention and social work reveals that concepts of crisis and time-limited services may be traced as far back as Bertha Reynolds' (1932) "short contacts", and treatment approaches to psychiatric casualties of World War I. From the Travellers Aid Society came the notion that:

A crisis which has just developed is far easier to resolve than one less abrupt in its development (Wilson, 1937, p. 64);

and from the "functional school" came the clear expectations regarding the use of time and the purpose of service, as described by Grace Marcus (1948).

The client with a problem he cannot meet without help is beset with crises...Because of some loss in his resources or some obstacle in himself or his circumstances....(he) cannot achieve the new organization of himself required to deal with his situation. The task of the caseworker is to help him mobilize his inner and outer forces, to handle his own problem (p. 234).

Charlotte Towle (1957) provided a statement about populations at risk:

Social work has always served families whose individual worlds have been stressful. Many... are vulnerable by reason of longstanding strain....Stresses become traumatic through repetition (p. 163).

Other social work contributions to crisis intervention

have come from Helen Harris Perlman, Lydia Rapoport, David Kaplan, Howard Parad, William Reid and Ann Shyne, Rosemary Lukton, Larry Smith, and Naomi Golan.

The conventional model of crisis intervention will be reviewed in terms of treatment goals, unit of attention, role and skills of the practitioner, manpower and training issues, and service delivery arrangements.

Objectives of Help - Most theorists include the following as long and short-term objectives of crisis intervention:

- 1) alleviation of the immediate impact of the disruptive stressful event;
- 2) restoration to optimal pre-crisis level of functioning;
- 3) initiation of new modes of perceiving and new adaptive coping responses. Here crisis intervention serves as primary prevention to the development of future crisis states.

Personality reorganization and characterological revampings are not considered legitimate objectives of the crisis approach. However, some psychoanalytically-oriented theorists suggest the "working through" of a current crisis situation may offer opportunities to master previously unresolved conflicts. This is indeed a desirable consequence, but it is not considered by any writer

to be a primary goal of the method.

Unit of Attention - The crisis model best typifies the duality of person-situation as the unit of attention in social work practice. The concept of crisis focuses our attention on external life events and institutionalized roles, as Bandler (1958) considers the personality as not necessarily dynamically relevant. The concept of coping on the other hand, has developed largely as an attribute of the organism--individual, family, and community--as Coelho, Hamburg and Adams (1974) concluded, "work on coping and adaptation arising in the disciplines of psychology and psychiatry has dealt in detail with the person, but very little with the environment" (p. 18).

Although applied to individuals, families, communities and society in general (Bonnefil & Jacobson, 1977), most crisis literature has focused on the individual and the family. There is somewhat less unanimity whether to regard community-wide disasters, epidemics, etc., as conceptually appropriate for the crisis model. Societal crises in economics, politics, education, the family--Meyer's (1971) "urban crisis"--are considered beyond the scope of most crisis literature.

The characteristics of the client groups and the nature of the crises are the primary indicators for determining whom to serve. Theoretically, all persons could

benefit from brief and focused intervention in time of stress, and Whittaker (1974) recommends the approach for people acutely in need of help. Rapoport (1970) feels that crisis intervention is most appropriate for persons with a prior state of adaptive functioning, experiencing acute conflictual problems, Porter (1966) agreed that clients most responsive to the crisis approach are those:

for whom the onset of the psychological problem is clear cut, whose prior level of adjustment was stable, for whom the crisis was generated out of a reciprocal role relationship, who have knowledge of the social and behavioral difficulties for which they seek help, and of the precipitating stress (p. 16).

Similarly, Golan (1974) offered three pivotal indicators for applying the crisis approach:

- 1) evidence of a clear cut hazardous event which has direct bearing on the client's state of disequilibrium;
- 2) a high level of anxiety and pain with demonstrated motivation and capacity for change;
- 3) evidence of a breakdown in problem-solving in the recent past.

Conversely, these criteria would exclude the following kinds of clients and situations:

Disordered individuals and families with character disorders or those in borderline states, where acting out and flight are major mechanisms of adaptation. Also not the treatment of choice for people with extremely marginal or low functioning of a chronic nature who need some sort of constant support (Rapoport, 1970, p. 272).

Golan (1974) refers to this group as:

Clients with severe and chronic ego depletion and damage who live in a chronic state of crisis....The crisis appearance is not a reaction to the original hazardous event but rather a maladaptive attempt to ward off underlying personality disturbances or psychosis. While such persons need help in emergencies, they do not seem to be able to engage in crisis resolution to develop more adaptive coping patterns (p. 442).

Golan (1974) also excludes clients without overt crisis symptoms, who produce crisis states in others, as well as persons who exist marginally in a state of chronic inability to cope with life's demands and require continuous support. LaVietes (1974) finds crisis intervention unsuitable for ghetto children, while Hollis (1972) notes its appropriateness for low-income groups.

Roles and Skills of the Practitioner - In view of the history, development and theoretical underpinnings of crisis intervention, it is not surprising that the primary method of helping is direct counseling and therapy. Siporin (1975) credits the crisis approach with moving social work away from the exclusive reliance on psychoanalytic and long-term approaches to treatment, and indeed, the clinician takes a more active, directive stance than in traditional psychodynamic treatment. The crisis therapist is more likely to give advice and to use limited goals, role rehearsal, anticipatory guidance, and environmental resources to enable his clients to cope with the

current distress.

A model of social worker-client interaction in crisis intervention is offered by Parad (1974):

- 1) worker attempts to alleviate disabling tension through ventilation and creation of a climate of trust and hope;
- 2) worker attempts to understand dynamics of the event that precipitated the crisis;
- 3) worker gives impression and understanding of the crisis and checks these perceptions with the client;
- 4) client and worker attempt to determine specific remedial measures to restore equilibrium;
- 5) introduction of new methods of coping;
- 6) termination after pre-determined number of interviews and/or agreed upon goals have been reached.

These are the well-known concepts and principles of crisis intervention which practitioners have relied upon and which have become a cornerstone of social work practice.

BEREAVEMENT COUNSELING

Crisis services for the bereaved have tended to take three forms: direct counseling by professionals, therapeutic activities sponsored or supervised by pro-

professionals, and self help programs without professionals.

It is important to note from the outset that the conceptual dilemmas noted in the earlier discussion of normal vs. pathological grief extends into the area of treatment as well. Thus, Worden (1982) differentiated between grief counseling which is intended to facilitate normal grieving and which may be conducted by non-professionals or volunteers (with supervision), and grief therapy for pathological grief to be provided by mental health clinicians only. A review of the principles and procedures of each approach is listed below:

Grief Counseling - Normal Grief

- 1) help the survivor actualize the loss
- 2) help the survivor identify and express feelings such as anger, guilt, sadness, anxiety and helplessness
- 3) assist living without the deceased
- 4) facilitate emotional withdrawal from the deceased
- 5) provide time to grieve

Grief Therapy - Pathological Grief

- 1) rule out physical disease
- 2) set up the contract and establish an alliance
- 3) revive memories of the deceased
- 4) assess which of the 4 grief tasks is not completed
- 5) deal with affect or lack of affect stimulated by memories

- | | |
|--|--|
| 6) interpret "normal" behavior | 6) explore and defuse linking objects (symbolic objects which keep connections to the deceased) |
| 7) allow for individual differences in grieving | 7) deal with the fantasy of ending grieving |
| 8) provide continuing support over an extended period of time | 8) help the patient say a final goodbye. |
| 9) examine defenses and coping styles | |
| 10) identify pathology and refer. | |

It is obvious that the amount of overlap between these two approaches is so extensive as to obviate the validity of the distinction itself. Yet, it clearly highlights the theoretical and service delivery confusion in the bereavement field. The majority of theorists and clinicians appear to use the terms bereavement counseling, grief counseling and grief therapy somewhat interchangeably to refer to direct interpersonal psychotherapy provided by a mental health professional.

Individual Counseling - For the most part, professional services to the bereaved have focused on counseling the individual adult. This is consistent with the grief formulation, the prevailing views of coping as a function of the personal attributes, and the traditional

emphasis on psychodynamic approaches to treatment. Doyle (1980) used the term grief counseling, Simos (1977) preferred grief therapy, and both included most of the treatment elements found in the preceding outline. Several specific individual therapy approaches to pathological grief are found in the literature (Arkin, et al., 1975). Volkan's (1975) "re-grief" therapy and Ramsay and Noorbergen's (1981) Guided Confrontation Therapy-GCT both view the pathological mourner as caught in a state of chronic hope (and dread) of reunion with the deceased, and treatment is an intense, sometimes daily regimen of persistent clarification and confrontation. In addition, a behavior modification approach to "bereavement behavior" is also found in the literature (Ramsay, 1977).

Since the bereavement counselor may encounter reactivated losses and concurrent personal and familial stresses, a workable distinction between grief treatment and general therapeutic help may not be practical.

Effectiveness research regarding grief counseling with individuals was reviewed by Parkes (1980). Raphael's (1977) study of supportive counseling with Australian widows found that a high-risk group could be identified by the perception of low social support. The high-risk widows in the treatment group were similar on outcome to the untreated low-risk group, attesting to the value

of supportive counseling in reducing predicted dysfunctional outcomes. Counseling with the elderly bereaved was studied by Gerber (1975) who found that a combination of office and telephone counseling resulted in better reported health and less contact with physicians among the treatment group.

Group Counseling - Group therapy with bereaved persons has received scant attention in the literature. Schwartz (1975) conceptualizes group approaches to stressful life situations as situation/transition (S/T) groups, and notes five identifying characteristics:

- (1) the S/T group is oriented toward helping members cope with some shared stressful event unlike groups which focus primarily on intrapersonal change, personal growth, insight, increased capacity for interpersonal living, socialization, etc. In addition, it is coping on a personal level rather than through activist approaches trying to rectify problems in the environment or in social institutions. Such organizations may develop from S/T groups;
- (2) the S/T groups have the properties of small groups, and meet regularly over a period of weeks or months. Membership ranges from 5-12 participants.

- (3) The S/T groups are moderated by a trained professional leader unlike conventional self-help groups;
- (4) the S/T groups offer social support, factual information about the shared life stress, and an opportunity for emotional interaction with others around the group focus. These three components will vary;
- (5) the S/T groups do not encourage or require members to espouse a particular moral or behavioral value system.

Schwartz (1975) categorized the helpful factors of S/T groups in terms of suppressive, expressive, and neutral functions:

- 1) Suppressive functions - the group is seen as a safe haven where members can be comforted by peers and a parental figure. Members experience universality and are free to explore and develop their own adaptive responses and defenses.
- 2) Expressive functions - the group offers a setting for the timely and appropriate verbalization and ventilation of feelings to reduce emotional distress.
- 3) Neutral functions - information sharing may be formal or informal and can help promote a

cognitive framework within which to structure events and feelings. Socialization counters loneliness and offers a sense of belonging.

Although there is no evidence in the literature that S/T groups were psychologically damaging to the participants, it may be assumed that the hazards found in other group situations are potential sources of danger with the vulnerable populations in S/T groups. Conversely, the therapeutic effects of these groups may mitigate further psychosocial distress and thereby serve a preventive function.

Only one study could be located which attempted to evaluate group treatment with the bereaved. Jones' unpublished doctoral dissertation (Univ. of California) focused on short-term (8 weeks) group therapy with widows and widowers. The author found evidence that the high-risk bereaved, those who felt guilt and blame, showed greater improvement than low-risk controls (Parkes, 1980).

Family Counseling - Family counseling with the bereaved has received somewhat less attention than counseling with individuals. Caroff and Dobrof (1975) viewed the family as the unit of attention in bereavement counseling and this broader approach allows the clinician to focus on the needs of all members including the extended family. While a specific family therapy approach

to bereavement is not reported in the literature, several formulations emphasize treatment procedures which encourage the open expression of distressing emotion and the need to reallocate, if possible, role expectations and performance among the surviving members.

The effectiveness literature contains only one research effort regarding family treatment with bereavement. Polak, et al., (1975) focused on the families of the bereaved due to sudden death, providing short-term counseling to promote effective coping. Finding no significant differences between the treated and untreated groups, the authors concluded that:

The techniques of social systems intervention presently available are not adequate to produce effective social change (p. 148).

Volunteer and Self-Help Programs

A variety of bereavement programs have developed using paraprofessionals and volunteers who are trained and supervised by health and mental health professionals.

The Widow to Widow Program, originally sponsored by the Harvard Laboratory of Community Psychiatry, was designed as a demonstration in preventing emotional problems in recently bereaved widows (Silverman, 1969). In this program, five "recovered" widow caregivers effectively reached out to 400 new widows in Boston's inner city, who on their own would not have requested services.

In addition to providing direct emotional support and reassurance, the aides were regarded as helpful in two ways: providing a role model of successful coping and enabling the widow to reach out to new populations of singles and other widows.

As the Widow to Widow experiment was coming to an end, a hot line was established to extend the support system for widowed persons throughout the Boston metropolitan area. In fact two of the five widow caregivers who had served in the outreach program became coordinators of the Widowed Service Line. In addition to reviewing the operation of this program, Abrahams (1976) provided an interesting analysis of the variety of helping roles among volunteers, designating four helping styles found in mutual aid relationships. These are: informative-supportive (non-self-revealing), emotive-supportive (non-self-revealing), emotive-supportive (some self-revealing), and integrative-friendship (self-revealing). She speculates that:

There was some indication that helpers may best help those recipients whose needs at the time of seeking help are closest to their own needs at that time. Any helper-recipient matching system would have to allow for constant fluctuation in the pattern of needs as both helpers and recipients move forward in their widowhood experience and recovery (Abrahams, 1976, p. 259).

Both the Widow to Widow Program and the Widowed Service Line lacked any form of systematic evaluation.

Other professionally sponsored bereavement programs reported in the literature are more limited in scope, but some do include evaluative components.

Volunteers provided emotional assistance to spouses of patients who died in two Manchester hospitals. The study reported that compared with a control group of other bereaved spouses, six to nine months after the death, no significant differences in state of health were evident (Parkes, 1980).

Parkes (1980) studied a volunteer service for relatives of patients dying at St. Christopher's Hospice in London. At one year past the bereavement, no differences were noted between the group receiving volunteer services and the control group. However, over the next three years, the supported group registered overall better scores on three measures of the state of health. High-risk bereaved people who were unsupported had significantly worse health scores than the low-risk bereaved, but little difference was noted between the high-risk supported group and the low-risk unsupported group. The author concluded that the effect of the volunteer service was to reduce the risk in the high-risk group to that of the low-risk bereaved.

The Naim Conference is a Catholic organization for widowed Catholics or spouses of deceased Catholics.

Modeled after the Cana Conference, the name of the organization was taken from the name of the town, Naim, where Jesus performed a miracle for the sake of a widow (Luke 7:11-13). Founded in 1956 by a remarried widow and widower, Naim has a current membership of 1,000 and is probably the country's oldest self-help organization for persons who have lost a spouse. Steinberg and Miles (1979) traced the transformation of Naim from an interpersonal group format, emphasizing catharsis and support, to a socially-oriented organization. Early in the organization's history, there was considerable opposition from the church regarding the provision of social outings and activities for the widowed. In addition, media exposure resulted in a problematic increase in membership. Older widowed persons, somewhat removed from their grief, became dissatisfied with bereavement-focused meetings. Some ten years after its inception, Naim functioned primarily as a social organization for its members, with the psychosocial needs of the newly-bereaved, a secondary issue.

Bankoff (1979) used the Naim organization to examine whether self-help programs represented an alternative to inadequate professional services, or a response to a nonsupportive social network.

Her survey revealed that Naim members were frequent

and consistent users of professional help and the expressed motivation of those who sought membership was not to achieve the mental health goals similar to those who seek professional psychotherapy, but rather to find social and pleasurable activities and relationships. Membership seemed more related to a perception of their social networks as less than adequate in times of crisis, and that relatives, friends and neighbors were less dependable.

Compassionate Friends was founded in England in 1969 by Reverend Simon Stephens, an Anglican chaplain serving in a hospital for terminally ill children. Stephens' book Death Comes Home which describes his work with one family, serves as an inspiration and ideological basis for the organization.

The aims stated at the first meeting were:

To offer friendship and understanding to any person, irrespective of color and creed, who finds himself or herself heartbroken and socially isolated by the death of a child (Stephens, 1972, p. 20).

It was hoped that the "ministry of compassion" would address the problems of many bereaved parents such as the gradual withdrawal of the family's social network after the initial grieving period, the 'conspiracy of silence' concerning death in modern society, the lack of training and sensitivity on the part of pro-

professionals serving bereaved families, and the unavailability of volunteers to help the bereaved.

The organization's rapid expansion in England was itself significantly augmented by activities in the U.S., especially the publication of Harriet Schiff's The Bereaved Parent, and her public appearance on the Phil Donahue talk show in 1977, which resulted in a 150% increase in the number of chapters within nine months of the broadcast.

The newly bereaved are invited to meetings four to six weeks after the death and currently there are 126 chapters meeting regularly. Strong emphasis is placed on sharing information, review of grief literature and vicarious learning based on the experiences of those who have survived their loss and made the transition to normal living again. Often during meetings, individual parents review their own successful adaptation (Davidson, 1979).

Sherman (1979) viewed Compassionate Friends in relation to the idea that self-help groups inculcate a special ideology which members regard as vital to their coping, and that this ideology functions as a cognitive antidote to common shared features of the problem. He notes that:

In coping with bereavement, the intention is not to eliminate grieving behavior, but rather to reconceptualize it and put it in an adaptive perspective...cognitive antidotes are required

not only to counter the attitudes and feelings around one's own behavior, but also to redirect the behavior of significant others (p.306).

In view of Sherman's (1979) analysis, it is interesting to consider that one research effort found no correlation between the emphasis on cognitive and rational mastery of bereavement (Compassionate Friends' ideology) and the perceptions and preferences of the members themselves. Lieberman (1979) surveyed bereaved parents who emphasized that more than anything else, the group meetings helped to universalize the experience, that the presence of veteran parents provided hope of accepting the ultimate loss, that existential matters could be addressed and that the opportunity for helping others was highly valued.

The National Sudden Infant Death Syndrome Foundation, Inc. (NSIDSF), formerly the Mark Addison Roe Foundation, was the first lay organization established for the purpose of publicizing the syndrome, and trying to raise funds for medical research. While each chapter is an extension of the Foundation itself and takes the responsibility for undertaking all of the activities of the national organization, a major focus is on serving parents who have lost infants to the syndrome. In addition, the chapters maintain close relationships with local medical, religious, and governmental authorities to pro-

mote greater understanding of SIDS and comparison for those who have suffered losses.

Thus, volunteer and self-help programs make an important, though generally untested, contribution to bereavement services. Although such programs occasionally take a competing or adversarial stance vis á vis professional services, they deserve recognition by clinicians as providing a variety of elements not available in the professional relationships.

CRITICISMS AND ALTERNATE MODELS OF CRISIS INTERVENTION
AND BEREAVEMENT COUNSELING

The clinical aspects of crisis theory derive from the proposed nature of life crises, general notions of professional helping, and one's philosophical and ideological view of man. As discussed earlier, many assumptions and concepts in the crisis literature have been challenged and/or refuted.

The unit of attention in crisis treatment has been described as too restrictive by Panzer (1978), too inclusive by other writers, and generally problematic by Golan (1974):

It has been my experience that whenever I think I have isolated a group for whom crisis intervention appears to be inappropriate, someone will report its usage for that group with signal success. Since crisis intervention is part of the short-term approach, it may well be that further clarification will have to await development of the parameters of this form of treatment (p. 443).

Equally lacking is an empirical base regarding effectiveness and outcome. Rapoport (1970) stated that "as yet, there is no systematic study of outcome at termination or of long term effects" (p. 41). Similarly, Gottschalk (1973) noted that:

We know of no controlled studies that have sought to demonstrate decisively that this important goal of crisis therapy (improved coping mechanisms in later life) has ever been attained (p. 1111).

The strongest justification for crisis intervention services is based on a variety of studies which concluded that:

- (1) there is no significant difference between time-limited psychotherapy and treatment which does not have this built-in constraint;
- (2) long waiting periods between a request for help and the assignment to a therapist are negatively related to outcome (Bloom, 1977).

Despite this, Mechanic (1969) indicated that, in general, the values of such therapies (crisis approaches) are difficult to determine and Bloom (1977) noted specifically that none of the research has verified that brief treatment at the time of crisis is more helpful than longer treatment after the crisis has passed.

The call for further research encompasses a full range of theoretical and methodological areas. Parad (1974) stated that the crucial task facing the profession (in this area) is to build up a cumulative body of knowledge via exploratory clinical action to provide systematic information about:

- (1) criteria for intervention
- (2) client's perception of the event
- (3) identification of crisis
- (4) specific treatment goals

- (5) client's and worker's perception of the time dimension
- (6) treatment techniques
- (7) perception of outcome.

Rapoport (1970) called for further work on:

- 1) operationalizing the definition of crisis
- 2) experimentation with different treatment modalities, target groups, social problems and time dimensions
- 3) a framework for diagnosing family crisis
- 4) studying the dynamics of change
- 5) delineating the particular tasks of specific crises
- 6) achieving a better blend of contributing theories.

In summary, while crisis intervention lacks many of the structural characteristics of a clinical theory (Fischer, 1978), and empirical validation of crisis concepts and principles is very limited, it does provide some working guidelines to practitioners and program planners.

An alternative approach to crisis intervention based on general systems theory yields different premises and postulates:

- 1. The key variable is whether an effective support system is provided to the individual or group experiencing the crisis.
- 2. Interaction between the personality of the individual in crisis and the crisis stimulus occurs in a social context.
- 3. Return of the individual to a homeostatic state may involve correcting ineffective or detrimental patterns of relating within his social system.

4. The focus of intervention should be on changing those current patterns of interaction that are maintaining the crisis.

5. Assessment of etiology is not relevant to crisis resolution.

6. Insight and awareness are not causal in producing change in current patterns of interaction (Umana, et al., 1980, p. 84).

Several theorists and clinicians have proposed the social network as the unit of attention, with network analysis and "networking", serving as diagnostic and treatment constructs (Cohen and Sokolovsky, 1979; Rueveni, 1979; Speck and Attneave, 1973; Tolsdorf, 1975).

Pattison's (1975) psychosocial model of family therapy suggests that just as family therapy extended the perspective in relation to the individual, network therapy broadened the approach in terms of the family.

Others view the individual or family within its social network, and clinical activity is directed towards three areas: (1) engaging and enhancing the existing network, (2) attaching the isolated person or family to their network, and (3) creating a new social network for the person or family. Within this framework, a variety of therapeutic approaches would be necessary and appropriate, including: network meetings, individual, group and family therapy, use of volunteer and "natural" helpers and involvement in self-help groups (Swenson, 1979).

APPLICATION CONCEPTS DERIVED FROM THE LITERATURE REVIEW

CRISIS INTERVENTION, BEREAVEMENT COUNSELING

& SOCIAL NETWORKING

10. Professional helping assumes not only a developed methodology and set of techniques, but an ideological and philosophical basis as well. The values and beliefs underlying a practice model should be explicit both in regard to the nature of the problem to be addressed, the nature of the proposed intervention, and the iatrogenic risks inherent in such activities.
11. Crisis intervention services should be provided only when the natural support system and coping abilities of the individual or family appear to be inadequate or actually failing.
12. Crisis intervention need not be limited to counseling and psychotherapy. Rather, it includes prevention as well as treatment and a variety of roles for the clinician, such as advocate, broker of services, educator and therapist.
13. Professional helping should be measured in order to assess effectiveness and the need for modification to increase knowledge and experience in the particular field, as well as to meet the mandates of funding sources.
14. The SIDS counselor or mental health professional

is but one in a network of helpers, which include health care workers, clergymen, paraprofessionals, volunteers, neighbors, friends and relatives. One aspect of the clinician's role is to orchestrate these therapeutic elements to foster achievement of the designated coping tasks.

15. The SIDS counselor is in a strategic position to activate and support the therapeutic aspects of the family social network, to help create supportive forces and groups outside the family, to help link the bereaved families with such organizations and resources, and to provide direct clinical service when indicated.
 16. The practice model with SIDS families adopts an ecological and systems theory perspective which views grief and mourning as a non-deterministic stress response, coping as an adaptive process influenced by forces ranging from societal ideologies to endocrine reactivity, and professional intervention as a secondary response to crisis, when individual, familial and network coping response and resources are inadequate. Thus, non-utilization of programs and services may be a sign of strength, rather than avoidance or lack of motivation or ability with SIDS families.
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THE SOCIAL NETWORKING PRACTICE MODEL WITH SIDS FAMILIES

The proposed practice model is a comprehensive statement about familial coping and professional intervention with bereavement due to Sudden Infant Death Syndrome.

Unlike traditional crisis theory, grief and mourning following the loss of a child are viewed in a less deterministic, less prescriptive framework in light of the variability which cross-cultural and cognitive studies indicate.

Differential coping results in a category of high-risk bereaved, whose vulnerability appears related to overall well-being and level of functioning prior to the infant's death, as well as limited actual or perceived support. When intervention by a professional is considered necessary (i.e., the existing network is inadequate or nonexistent), it focuses on the same coping tasks that natural coping engenders.

The SIDS professional assumes the role of orchestrator of social network actors and forces with the intent of enabling the family member to more effectively handle the designated tasks. In addition to the centrality of the coping tasks, the professional needs to make available three kinds of helpers: the expert, the veteran, and the peer, and the latter two may be effectively handled by training and deploying previously bereaved parents

to serve as counselors and by providing parent meetings for the newly bereaved.

The psychotherapeutic element emphasizes universalizing the grief response and devising cognitive antidotes to reduce blame and guilt. The social networking efforts focus on sensitizing, activating, linking and creating social support.

METHODOLOGY

Chapter IV

A. RESEARCH DESIGN

Developmental research has been described as:

A new and different paradigm of inquiry, inasmuch as it places primary emphasis on those methods by which interventional innovations and other aspects of social technology are analyzed, designed, created and evaluated...This emerging model of research is to be contrasted with the more familiar behavioral science model oriented toward building knowledge about human behavior (Thomas, 1980, p. 91).

This methodology, it was felt, could best address the theoretical and conceptual difficulties in the field of bereavement, as well as generate practice strategies to better serve SIDS families. Secondary benefits would include clarification of clinical and programatic issues in crisis intervention and refinement of research efforts in thanatology.

The testing of a practice model derives its methods from program evaluation theory (Rothman, 1980). The basic components of evaluation research (Weiss, 1972) are:

- 1) the use of a systematic methodology
- 2) the assessment of outcomes
- 3) the establishment of specific criteria
upon which to base objective outcome
assessments

- 4) the contribution of this information to social purposes.

The ideal research design is one which will accurately answer the questions posed for study while remaining sensitive and appropriate to the needs of the subjects and setting within which the research is conducted (Shontz, 1986).

To best address these concerns, a two-group comparative experimental design was selected to study the outcomes of conventional bereavement counseling and the proposed social networking practice model. It should be noted that this project represents the first known comparative treatment study in the field of bereavement and only the third effort to investigate intervention of any kind with SIDS bereaved families.

Due to the absence of a no-treatment control group, this design does not provide evidence of the benefits of the experimental or conventional approach over no treatment at all. Assigning severely traumatized families to such a true control group was ethically and clinically unacceptable and on a practical basis, service-refusing families were too few or unavailable in general, to be surveyed.

B. SETTING AND SAMPLE

The study was conducted under the auspices of the

New York City Information and Counseling Program for Sudden Infant Death, a project of Medical and Health Research Association of New York, Inc. The SIDS Program is co-sponsored by the Office of the Chief Medical Examiner and the New York City Department of Health. The principal investigator has served as Mental Health Consultant to the Program since 1980, and since 1981 has single-handedly staffed the satellite office established at Kings County Hospital in Brooklyn.

The Brooklyn SIDS office serves all Brooklyn and many Queens families, usually totalling 100-125 cases annually. This number represents approximately one-half of the total SIDS cases reported in the five boroughs, with the main office (Office of Chief Medical Examiner) responsible for Bronx, Manhattan, Richmond and some Queens families. Administrative and clerical activities are provided by the main office.

Following the post-mortem findings, families are called by a SIDS counselor (usually within forty-eight hours of the infant's death). Contact with families with no home phone occurs via mail (SIDS and bereavement literature) and by public health nurse home visits.

Services provided include: office and telephone counseling, SIDS and bereavement literature, public health nurse visits, parent group meetings and parent contacts.

Families served by the Brooklyn office are demographically identical to the population served by the main office. Thus, lower class and minority families are overrepresented among the SIDS population, a significant proportion of the families are single parents and adolescent mothers account for nearly one-third of the total.

In terms of the actual sampling, during the initial interview, an informal assessment was made of significant network members perceived positively or negatively (including those not involved). Following agreement to participate, the list was further developed in each of three sectors with the mother rating the person as helpful, unhelpful or uninvolved. The criterion for inclusion in the study and for consideration as a "high-risk" situation was twenty-five percent or more of network members perceived as unhelpful or uninvolved. This parameter was obtained by asking other NYC SIDS clinicians to estimate in approximately twenty current, problematic treatment cases, the initial percentage of unhelpful network members.

Twenty-two cases were excluded from the study according to the following criteria:

- 1) 5 non-English-speaking families
- 2) 1 family with a second SIDS loss

- 3) 1 family where the deceased was adopted
- 4) 1 family where the deceased was in foster care
- 5) 4 families declined participation
- 6) 10 families who were not considered "high-risk" bereaved.

This sixth exclusion category--non-high-risk bereaved--addresses one of the major conceptual and methodologic problems in bereavement research. There is empirical evidence as well as lay appreciation that the majority of bereaved persons do not evidence long-term psychosocial damage. A corollary of this is the expectation that the emotional, cognitive and physiologic distress which comprises grieving will follow a downward trajectory over time. In fact, one study of SIDS bereavement used a grief scale administered over a one-year period and proposed that any variation in scores other than an overall decline was indicative of dysfunction (Lowman, 1979).

Thus, since the natural course of the phenomenon could obscure treatment effects, it was decided that the study would focus on those families whose grief and mourning would not be expected to proceed uneventfully. The search for high-risk factors yielded the well-established predictors of poor outcome: general pre-morbid functioning, past or present psychiatric illness, substance abuse or major stressors and social isolation.

The last factor, social isolation, was selected as the criterion for "high risk" status (and subsequent inclusion in the study) for three reasons:

- a) social isolation has been repeatedly implicated as a stressor;
- b) clinical experience with nearly 500 bereaved families suggested that the lack of social support has been a major factor in dysfunctional coping; and
- c) a composite measure of all pertinent risk variables would have been too difficult to construct and operationalize.

One might speculate that the mysterious nature of the death, the societal suspicion of homicide and the parents' self-scrutinizing blame and guilt intensify the impact of social isolation (and social support) on the coping process. In fact, this emphasis on the social response to and context of the SIDS loss formed the basis for the rationale and clinical methods of the practice model developed in this study.

Lastly, social isolation and social support are multifaceted concepts. The research and clinical evidence suggested that the perception of support, not simply the objective counting of network members, would be the more appropriate and useful approach (Albrecht & Adelman,

1987). Therefore, inclusion in the study which signifies "high-risk" status, reflects a perception of compromised social support as measured on the Perception of Social Support Index. (This will be described further in the DEPENDENT VARIABLES section.)

The final sample of sixty "high risk" families was drawn from the population of all SIDS deaths reported to the Brooklyn satellite office during the period of January to October 1985, a total of 82 cases.

Mothers were randomly assigned to the conventional or experimental treatment group if they met the criteria for "high risk" as measured by the Perception of Social Support Index. Since there is no reason to assume that the infant deaths occurred in a predictable or biased manner, the randomization insured representativeness. Also, since only four of sixty families declined participation, it was felt that the representativeness of the sample had not been jeopardized. Overall, nearly three-quarters of the mothers interviewed were considered appropriate for the study.

The data presented in Table 1 confirms that the two groups were comparable and evenly matched on the major demographic factors.

TABLE 1 - DEMOGRAPHIC DATA FOR ALL CASES (N=60)

| | | (N=30) | (N=30) |
|---|---------------|-------------------|---------------------|
| <u>Variable</u> | | <u>Networking</u> | <u>Conventional</u> |
| <u>MATERNAL AGE</u> | | 18-36 (range) | 15-42 (range) |
| | | 22.8 (mean) | 22.6 (mean) |
| | | 4.3 (std. dev.) | 5.3 (std. dev.) |
| | | <u>PERCENT</u> | <u>PERCENT</u> |
| <u>MARITAL STATUS</u> | Married | 36.7 | 40.0 |
| | Single | 60.0 | 53.0 |
| | Sep./Div. | 3.3 | 7.0 |
| | Upper Mid. | 10.0 | 10.0 |
| <u>SOCIO-ECONOMIC STATUS:</u> | Upper Low | 33.3 | 40.0 |
| | Lower Low | 23.3 | 6.7 |
| | ADC | 33.3 | 43.3 |
| | ADC | 33.3 | 43.3 |
| <u>RACE:</u> | Black | 76.7 | 46.7 |
| | White | 6.7 | 20.0 |
| | Hisp. | 16.7 | 30.3 |
| | Oth. | 0.0 | 3.0 |
| <u>RELIGION:</u> | Prot. | 70.0 | 53.0 |
| | Cath. | 30.0 | 40.0 |
| | Jew. | 0.0 | 3.3 |
| | Oth. | 0.0 | 3.3 |
| <u>AGE OF DEC.</u> | | 1-11 mos. (range) | 1-21 mos. (range) |
| | | 3.3 mos. (mean) | 3.9 mos. (mean) |
| | | 2.2 mos. (SD) | 3.7 mos. (SD) |
| <u>SURVIVING SIB.</u> | 0 | 46.7 | 46.7 |
| | 1 | 36.7 | 33.3 |
| | 2 | 10.0 | 13.3 |
| | 3+ | 6.7 | 6.7 |
| <u>STRESS AREAS:</u> (Families reporting stress) | Medical | 53.3 | 56.7 |
| | Psych | 43.3 | 36.7 |
| | Interpersonal | 66.7 | 66.7 |
| | Legal | 20.0 | 16.7 |
| | Financial | 20.0 | 36.7 |
| | Work | 33.3 | 30.0 |
| | Housing | 43.3 | 30.0 |
| | Other | 10.0 | 10.0 |

C. DATA COLLECTION

The data collection took place within the context of providing clinical services to the bereaved families. The initial home visit occurred within two weeks of the infant's death and always after the funeral. The latter is significant in that many low-income and AFDC-supported families experience significant turmoil over being unable to afford the kind of funeral for their baby which respects and assuages personal, familial and reference group expectations. (Technical assistance is provided by the SIDS staff regarding the Dept. of Social Services funeral reimbursement program during the initial phone call.) By the end of the two-week period, the funeral crisis has subsided and the family's regular lifestyle (return to work, decline in visitation, etc.) has begun to reshape.

These initial interviews with the mothers were identical to the format used with families prior to the initiation of the study. A combination of assessment and intervention efforts were used to:

- a) review the circumstances of the infant's death, to encourage ventilation of emotional distress and growing acceptance of the loss. Troubling images of the death scene and the perception of emergency personnel are elicited as these often become pathologic forces in the coping process;

- b) review the Medical Examiner's cause of death

providing additional clinical and epidemiologic information to substantiate SIDS and to counter other attribution processes involving self or other blame. Anecdotes demonstrating the lack of predictability, preventability and rescue often result in immediate, visible relief from anguish and guilt;

c) clarification of current social support with special attention focused on perceived blame from relatives, friends and others;

d) discussion of current and previous stressors and characteristic coping patterns, especially regarding experiences of death and loss but also considering medical, economic, legal, work, housing, psychiatric and familial difficulties;

e) discussion of grief and mourning reactions, assessing biopsychosocial reactions, age (siblings of infant), gender (father of infant) and relationship (grandparents, babysitter, etc.) variations. Interventions at this point involve reassurance and acceptance of reactions along with sharing previously documented and clinically observed responses of similarly bereaved parents;

f) explanation of services offered by the agency, with a tentative plan of contact agreed upon.

With these issues addressed and with the mother's

emotional state appropriate and receptive, the clinician/researcher introduced the idea of a study to improve the Program's efforts to help families. Emphatic statements were repeated that lack of participation would in no way compromise services provided and the previously agreed upon plan of contact, as well as the supportive and lengthy visit, contributed to willing participation by the large majority of families. All mothers signed a consent form reiterating the above and were sent xerox copies.

The interview would then continue with the use of three self-report instruments regarding perception of social support, grief reactions and blame for the infant's death, usually completed within a half-hour.

Subsequent research-inclusive interviews were scheduled for three months and six months following the infant's death, though the therapeutic needs of the mother and family remained primary during the interim periods as well as after the six-month point.

In addition, a fourth instrument measuring role functioning was administered only at the three- and six-month contacts. Since this measure was an attempt to tap overall psychosocial well-being, it was considered valid only after the upheaval and confusion of the acute grief period had subsided. Its absence at the first

visit also reduced the cognitive and time demands placed on the mother.

D. VARIABLES AND MEASURES

Concepts are general codifications of experience and observations, and in science these collections of related attributes are termed variables (Babbie, 1973). Operationalization is the process whereby the researcher specifies empirical observations that may be regarded as indicators of the attributes comprising the concept.

In developmental research, the independent and dependent variables are associated with the testing phase of model development, and are derived from the same conceptual base. In this study, the independent variables were conventional bereavement counseling and the experimental social networking practice model.

1. INDEPENDENT VARIABLES

It is important to clarify that the two treatment approaches being compared in this study are not mutually exclusive models of intervention. The social networking model of practice derived from the R & D literature review and clinical experience included all of the services and counseling activities of the conventional approach, with the addition of planned and extensive networking

techniques to achieve a better bereavement outcome.

There are, to be sure, different ideological and conceptual premises for each approach which were presented in the previous review.

CONVENTIONAL BEREAVEMENT COUNSELING

The current practice model of NYC SIDS Program involves the provision of direct services to bereaved families using five modalities: office-based counseling (individual/family), group counseling, telephone counseling, SIDS and grief/mourning literature and home visits by public health nurses (in liaison with the SIDS Program). There are no restrictions or fees involved.

The counseling efforts focus on:

- a) explaining the cause of death to reduce guilt and blame
- b) supporting and universalizing grief reactions
- c) addressing current stressors
- d) restoring role functioning.

Individuals and families make use of any combination of services and the general agency policy is based on "reaching out" unless the family is not in need of or not accepting of services. The majority of families do not make long-term use of the program, with many requiring only several phone calls or interviews.

THE SOCIAL NETWORKING MODEL

As noted earlier, the networking approach incorporated all of the conventional SIDS services, methods and goals. In addition, the model emphasizes the vital importance of social support in the coping process. Clinical efforts are focused on enhancement, linkage to and/or creation of network resources. Thus, interviews, phone calls and SIDS literature are used with the three network sectors (kin, friends and professionals) yielding nine additional interventions. The tenth intervention (a total of fifteen) is the availability of parent contacts, that is, previously bereaved volunteer parents who are at least one year past the infant's death, who demonstrate the interest and aptitude to help the newly bereaved, and who complete a staff training course. The use of parent contacts, based on Riesman's "Helper-Therapy" principle (Riessman, 1965) represents a created, artificial network as opposed to the existing natural one.

The quantitative and qualitative aspects of both models were compared by tallying the number or percentage of each service activity and by recording significant themes and issues in the phone and interview counseling sessions. The data is presented both by TYPE of intervention as well as FOCUS of intervention in Tables 2-11:

TYPE OF INTERVENTION

Table 2 - Total Number, Mean and Range of All Counseling Interviews

| | N | Mothers | Kin | Friends | Profes- sionals | Total | Range | Mean |
|----------------|----|---------|-----|---------|--------------------|-------|-------|------|
| CONVENTIONAL - | 30 | 69 | 10 | 2 | 0 | 81 | 0-4 | 2.3 |
| NETWORKING - | 30 | 74 | 24 | 1 | 4 | 103 | 2-7 | 2.5 |

Table 3 - Total Number, Mean and Range of All Telephone Counseling Calls

| | N | Mothers | Kin | Friends | Profes- sionals | Total | Range | Mean for Mothers | Mean for Network |
|----------------|----|---------|-----|---------|--------------------|-------|-------|---------------------|---------------------|
| CONVENTIONAL - | 30 | 72 | 11 | 0 | 2 | 85 | 0-5 | 2.4 | .4 |
| NETWORKING - | 30 | 65 | 54 | 24 | 31 | 174 | 0-5 | 2.2 | 3.6 |

Table 4 - Total Number of SIDS Literature Packets Mailed

| | N | Mothers | Kin | Friends | Professionals | Total |
|----------------|----|---------|-----|---------|---------------|-------|
| CONVENTIONAL - | 30 | 30 | 15 | 0 | 0 | 45 |
| NETWORKING - | 30 | 30 | 99 | 61 | 26 | 216 |

Table 5 - Percentage of SIDS Families Receiving Specified Number (0-2)
Home Visits by Public Health Nurses

| | N | # of Visits: | 0 | 1 | 2 | |
|----------------|----|--------------|-------|-------|-------|------|
| CONVENTIONAL - | 30 | | 23.3% | 76.7% | 0.0% | 100% |
| NETWORKING - | 30 | | 26.7% | 53.3% | 20.0% | 100% |

Table 6 - Number of Parents Having Attended at Least 1 Parent Group
Meeting During Course of Study, Range for Each Group
and Percent of Each Group Who Never Attended

| | N | # Attended | Range | % Never Attended |
|----------------|----|------------|-------|------------------|
| CONVENTIONAL - | 30 | 21 | 0-2 | 50.0 |
| NETWORKING - | 30 | 18 | 0-3 | 63.3 |

Table 7 - Total Number, Mean and Range of Referrals for Other Services

| | <u>N</u> | <u>Total</u> | <u>Range</u> | <u>Mean</u> |
|----------------|----------|--------------|--------------|-------------|
| CONVENTIONAL - | 30 | 29 | 0-4 | .9 |
| NETWORKING - | 30 | 37 | 0-3 | 1.2 |

FOCUS OF INTERVENTIONTable 8 - Total Number of Interviews, Phone Calls and Literature Packets Provided for Mothers

| | | <u>MOTHER</u> | | |
|----------------|----------|-------------------|--------------------|---------------------------|
| | <u>N</u> | <u>Interviews</u> | <u>Phone Calls</u> | <u>Literature Packets</u> |
| CONVENTIONAL - | 30 | 69 | 72 | 30 |
| NETWORKING - | 30 | 74 | 65 | 30 |

Table 9 - Total Number of Interviews, Phone Calls and Literature Packets Provided for Kin

| | | <u>KIN</u> | | |
|----------------|----------|-------------------|--------------------|---------------------------|
| | <u>N</u> | <u>Interviews</u> | <u>Phone Calls</u> | <u>Literature Packets</u> |
| CONVENTIONAL - | 30 | 10 | 11 | 15 |
| NETWORKING - | 30 | 24 | 54 | 99 |

Table 10 - Total Number of Interviews, Phone Calls and Literature Packets Provided for Friends

| | | <u>FRIENDS</u> | | |
|----------------|----------|-------------------|--------------------|---------------------------|
| | <u>N</u> | <u>Interviews</u> | <u>Phone Calls</u> | <u>Literature Packets</u> |
| CONVENTIONAL - | 30 | 2 | 0 | 0 |
| NETWORKING - | 30 | 1 | 24 | 61 |

Table 11 - Total Number of Interviews, Phone Calls and Literature Packets Provided for Professionals

| | | <u>PROFESSIONALS</u> | | |
|----------------|----------|----------------------|--------------------|---------------------------|
| | <u>N</u> | <u>Interviews</u> | <u>Phone Calls</u> | <u>Literature Packets</u> |
| CONVENTIONAL - | 30 | 0 | 2 | 0 |
| NETWORKING - | 30 | 4 | 31 | 26 |

The data suggest that bereaved mothers in the conventional and networking groups received nearly equal numbers of counseling interviews, group sessions, phone sessions, literature packets and referrals to other agencies. The two groups are differentiated, however, by the interventions with members of the kinship, friendship and caregivers sectors of the social network. Thus, for the networking model, kin of the bereaved mother totaled more than twice the number of counseling sessions, almost five times the number of phone calls and more than six times the number of literature packets. In the friends and caregivers sectors, there were major differences between the two groups in terms of greater numbers of phone calls (24-0 friends, 31-2 professionals) and literature packets (61-0 friends, 26-0 professionals). The mothers in the networking group were slightly more likely to receive an additional nursing home visit, but were slightly less likely to attend the monthly parent group.

2. DEPENDENT VARIABLES

The dependent or outcome variables were the perception of social support, grief, the attribution of blame and role functioning (the elimination of the latter to be reviewed shortly).

In order to determine the associations between or among variables, it becomes necessary to use various methods of measurements. The adequacy of these procedures depends on two considerations--the degree to which the measures are free from error and the degree to which the measures reflect what one is looking for (Kogan, 1975). In addition to reliability and validity, measurement procedures should be evaluated regarding the ethical and practical aspects of data collection. Face validity, reliability coefficients and related issues are presented for each variable. It should be noted that reliability coefficients gauge the internal consistency of the index or scale (coefficient Alpha) with an acceptable level of reliability being .70. Measures with lower reliability reflect greater measurement error and may signal that the instrument is not measuring a conceptually unified construct (Nunnally, 1978).

The construction of measures for complicated or ambiguous variables like grief, attribution, social support and role performance requires instruments which are cumulative or composite in nature. In contrast to single-item questionnaires, scales and indices: a) more adequately represent complexity, b) enable the researcher to use ordinal levels and categories, and c) to allow for data-reduction and efficiency in the analysis of information.

A major consideration in the selection/development of instruments to measure the above-noted variables was concern for the emotional well-being of the bereaved mothers. The majority of SIDS studies have used retrospective mail surveys involving lengthy and detailed questionnaires (Burns, 1986; Crichton, 1982; Dyregrove & Matthiesen, 1987; Williams & Nikolaisen, 1983). Often the parents were 3-6 years past the death of their babies and are presumably able to cognitively attend to such a task.

However, in the present investigation, the initial interview with the SIDS mother occurred less than two weeks after the loss. Respondents were sometimes numb, preoccupied, hypervigilant and unable to sustain attention or clearly express feelings and attitudes. The search for existing instruments to measure the key variables sought brief, uncomplicated formats which would not further tax the mothers, while still maintaining scientific validity and reliability. For the most part, such instruments were not available and it was, therefore, necessary to design measures which would be acceptable, perhaps even helpful to the grieving parents, but which were admittedly less rigorous than established instrumentation. Thus, the alphas for inter-item reliability were too low to dependably discern true variance from error variance

in the measures of grief, blame and attribution.

Analysis of the Texas Inventory of Grief yielded moderate coefficients and the Perception of Social Support instrument is not measurable via inter-item methodology as it represents a singular calculation of percent supportive. It should be noted that reliability of the instruments could not be established via test/re-test methods as the study expected change over time as a result of the interventions.

SOCIAL SUPPORT

To think of life without any supportive relationships is to think of a profoundly isolated and difficult life indeed....Certainly the hundreds of studies published in just the past five years across the social and health sciences have shown links between objective and subjective qualities of relationships and well-being.... Among the most noteworthy findings have been that supportive relationships can reduce pregnancy complications and recovery from illness, protect against clinical depression or deviant behavior, reduce the risk of suicide, decrease psychological and physiological stress symptoms from work pressures and bereavement experiences, assist in the adaptation to change, encourage behavioral commitment to prescribed medical regimens, and promote the use of community health services....Similarly, the loss of social support or disruption in social ties has been associated with such pathologies as disease and depression, and deviant, abusive behavior to self and others (Adelman and Albrecht, 1987, p. 7).

The measurement of social support traditionally focused on the quantity of supportive interactions, the nature,

quality or locus of each support and lastly, the perception of any or all of the above. Operationalizing this variable was accomplished by: (a) focusing on the perception of social support since research has shown that subjective evaluations of network relationships are more strongly correlated with well-being than quantitative assessments of support (Ward, et al., 1984), and (b) locating the support within the context of the respondent's social network. A measure of perceived social support was constructed based on Pattison's (1975) model of family therapy, which designated three network sectors as the sources of support: kinship, friendship and caregivers.

Figure 2 displays the data sheet used for the Perception of Social Support Scale. Each network member mentioned by the mother was rated (helpful, unhelpful or uninvolved) and all three sectors were tallied to determine the percent of network members perceived to be unhelpful or uninvolved (lack of support).

As noted before, a percentage of 25% or greater lack of support was considered the criterion for participation in the study, thereby operationalizing the concept of high-risk.

The calculation of the PSS Scale scores were not weighted among the three sectors as one cannot assume

Figure 2. Perception of Social Support Scale

| SCORE: _____ (percentage perceived as unhelpful, uninvolved) | | | | husband/boyfriend, children, grandparent, sibling, other relative. | | | |
|--|----------------|------------------|-------------------|--|----------------|------------------|-------------------|
| <u>KINSHIP</u> | <u>Helpful</u> | <u>Unhelpful</u> | <u>Uninvolved</u> | <u>FRIENDSHIP</u> | <u>Helpful</u> | <u>Unhelpful</u> | <u>Uninvolved</u> |
| 1. | | | | 1. Babysitter | | | |
| 2. | | | | 2. Friend | | | |
| 3. | | | | 3. Friend | | | |
| 4. | | | | 4. Friend | | | |
| 5. | | | | 5. Friend | | | |
| 6. | | | | 6. Friend | | | |
| 7. | | | | 7. Friend | | | |
| 8. | | | | 8. Neighbor | | | |
| 9. | | | | 9. Neighbor | | | |
| 10. | | | | 10. Neighbor | | | |
| 11. | | | | 11. Co-worker | | | |
| 12. | | | | 12. Co-worker | | | |
| 13. | | | | 13. Co-worker | | | |
| 14. | | | | | | | |
| 15. | | | | <u>PROFESSIONALS</u> | | | |
| 16. | | | | 1. Physician | | | |
| 17. | | | | 2. Physician | | | |
| 18. | | | | 3. Nurse | | | |
| | | | | 4. Nurse | | | |
| | | | | 5. Other Health Professional | | | |
| | | | | 6. Mental Health Professional | | | |
| | | | | 7. Clergyman | | | |
| | | | | 8. Emergency Personnel | | | |
| | | | | 9. Emergency Personnel | | | |
| | | | | 10. Emergency Personnel | | | |

that the lack of support or a critical stance is inherently more damaging from any given sector.

GRIEF

Grief is a multidimensional phenomenon consisting of well-documented affective, cognitive, behavioral, social and biologic responses to loss. While these components are often manifested individually in daily living and in numerous psychiatric conditions, their emergence as a group or cluster following an actual or perceived loss is conceptualized as grief.

GRIEF SCALE

The Texas Inventory of Grief (Faschingbauer, 1972), is a six-item, yes/no, self or other-administered instrument which consists of:

- | | | |
|---|-----|----|
| 1. Have you felt so sad, discouraged ("down") or hopeless that you wondered if anything was worthwhile? | Yes | No |
| 2. Have you had a loss of appetite? | Yes | No |
| 3. Have you had any trouble in getting to sleep or staying asleep? | Yes | No |
| 4. Have you noticed feeling more irritable (fidgety, tense, restless) than usual? | Yes | No |
| 5. Have you found that you could think of hardly anything else except what happened to your baby and about him/her? | Yes | No |

6. Have you noticed any problems in taking care of things (carrying out your usual schedule of activities) because you just couldn't seem to "get going"? Yes No

The inventory taps affective, cognitive, behavioral and physiologic aspects of grieving, thereby showing appropriate variety in item selection, and attesting to the instrument's face validity. The inter-item reliability coefficients (coefficient alpha) are calculated at each data collection point with the elimination of item #4 due to low correlation with the other items. This item, irritability/anger, also seemed clinically absent among the majority of SIDS families, with the exception of cases where the infant's death was attributed to poor medical care (despite the SIDS diagnosis). At the first data point, the adjusted coefficient was .6322, at the second point, .4426 and at the third point, .5543. Again, these fairly low levels suggest that grief phenomena do not represent a unitary construct for measurement purposes.

ATTRIBUTION

Attribution theory and its clinical counterpart, cognitive therapeutics, postulate that stress is mediated by the meanings, perceptions and appraisals which are attached to events and situations. The attribution process has long been regarded as a major component in coping

with stressful life experiences.

For parents of SIDS infants, attribution takes on a fundamental intensity, as the mysterious nature of the death almost always provokes feelings of self-blame and guilt. SIDS bereavement appears to represent an exception to the research findings that taking responsibility for accidents and traumas is associated with a more favorable healing process and better psychosocial outcome (Wortman & Silver, 1987). In fact, clinical experience with hundreds of SIDS families suggested that any explanation which the family adopted apart from self or other blame was associated with a more positive outcome, even if the formal medical explanation was not accepted. Conversely, parents who persisted in blaming themselves, blaming a physician or health provider or who were blamed by significant others characteristically experienced problems of greater frequency, intensity and duration.

Review of the literature indicated no existing instruments specifically addressing the blame issues outlined above. Therefore, an attribution index was constructed, with item selection consisting of one question for each type of blame. The items were weighted equally and a five-point Likert scoring system was used:

ATTRIBUTION INDEX

1. To what extent have you been blamed by others for the baby's death

Not at all A little bit A moderate amount A great deal

1 2 3 4

2. To what extent do you blame others for the baby's death?

Not at all A little bit A moderate amount A great deal

1 2 3 4

3. To what extent do you blame yourself for the baby's death?

Not at all A little bit A moderate amount A great deal

1 2 3 4

The content validity reflects the simple and direct nature of the items, though the inter-item reliability coefficients (Alpha) of the measure proved to be too low to combine the three types of blame into an index. (Attribution at pt. 1 = .15, pt. 2 = .11, and pt. 3 = .13). Therefore, the three items were treated as separate measures in the analysis of the data, under the headings of BLAME BY OTHERS, BLAMING OTHERS, and SELF-BLAME.

ROLE FUNCTIONING

Whereas the first two dependent variables measured outcome in terms of reduced specific distress (grief, blame), it was felt that the third variable should reflect a more positive and broad aspect of coping. The concept

of social role has been long associated with personality development and overall mental health. As Helen Harris Perlman (1968) noted:

By vital roles is meant those that become so interlaced with the personality, so deep-driving in their significance to the person's feelings, perceptions, self-concept interpersonal relations that they are essential to his total well-being (p. 43).

Of the numerous dimensions of the role concept described in the sociological, anthropological and psychological literatures (role sharing, enactment, identification, strain, conflict, power, etc.), role competence was selected to facilitate the research subjects' self-rating of their functioning and well-being (Nye, 1976). In addition, theoretically the resumption of positive role functioning might signal a diminution of grieving and other emotional distress, perhaps yielding interesting correlations.

In constructing the index, it was necessary to consider all of the possible vital roles available to adolescent and young adult bereaved mothers. These included: parent (siblings of deceased), spouse/girlfriend, daughter, relative, worker, student, friend and neighbor. The selection of these roles follows the structural rather than interactionist perspective and the reference group to evaluate one's own competence would be determined by the respondent.

Again, Likert-type, self-rated measurement was used with all roles equally weighted, as one cannot assume that any role is inherently more important to the individual's self-image. Scoring is based on totaling the scores and dividing by the number of roles applicable.

A. How would you rate yourself as a worker
(at your job)?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

B. How would you rate yourself as a student?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

C. How would you rate yourself as a friend?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

D. How would you rate yourself as a neighbor?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

E. How would you rate yourself as a daughter?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

F. How would you rate yourself as a relative?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

G. Overall, how would you rate yourself as a wife/girlfriend?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

H. How would you rate yourself in terms of parenting?

| | | | | |
|------|------|---------|------|-----------|
| Poor | Fair | Average | Good | Excellent |
| 1 | 2 | 3 | 4 | 5 |

As noted before, the Index of Role Performance was constructed with the hypothesis that tapping the self-reported performance of one's major roles might function as an overall indicator of psychosocial well-functioning. The initial reliability analysis indicated that the coefficients for the overall measure were too low to establish internal consistency of the instrument. Further exploration of the measure's possible usefulness was conducted via inter-correlation yielding: a) a significant negative correlation between the roles of worker and student at the second data collection point, b) a significant positive correlation between the roles of daughter and relative, also at the second data collection point, and c) a significant positive correlation between the roles of friend, neighbor and wife/girlfriend at the third data collection point. The lack of consistency over the two data points is further evidence of the instrument's deficiency. The correlations are conceptually

understandable: (a) respondents were likely to be either workers or students, (b) fulfilling or not fulfilling the obligations of daughter role would seem to carry over to other obligatory family relationships, and (c) interpersonal relatedness whether in a marriage, intimate relationship, friendship or neighborliness might be expected to correlate.

Although it would have been possible to treat the items in the index separately (as was done with the Attribution Index), this would have been problematic in two ways. First, since none of the mothers occupied all of the roles, pursuing this analysis would have resulted in a markedly reduced N. Moreover, separate measures for each role would not have yielded the overall measure of mental health which would have augmented the assessment of grief, attribution and social support. The inclusion of the instrument, therefore, appeared to add little meaningful data to the study and was, therefore, eliminated from the analysis.

CONCLUSION

This study used R & D concepts to develop a practice model for bereaved families and to test such in a comparative treatment design. Several methodologic, clinical and ethical issues in this undertaking have been outlined.

One significant limitation was the compromised scientific reliability of the instruments developed for the dependent variables. Both in construction (Attribution Index) and conceptualization (Index of Role Performance) the measures yielded unacceptably low coefficient alphas (with the latter measure ultimately eliminated). Unfortunately, the established instrumentation in these areas were simply too lengthy and complex to administer in recently traumatized persons. Clearly, the interpretation of the findings needs to acknowledge this, though Cowger and Kagle (1979) offer the following:

It is not necessary that methodologically flawed research be withheld. On the contrary, research that takes place in the real world typically must sacrifice scientific rigor for validity (p. 88-89).

A final methodologic issue concerns the potentially biasing effect of the data collection and intervention having both been conducted by the author. Several safeguards were established:

- 1) The instruments chosen were of the self-report type and were simply scored by the author.
- 2) The proposed treatment approaches were differentiated primarily on a quantitative basis insofar as the same interventions of the conventional model (counseling,

phone calls and literature) were extended to the social network in the experimental model.

- 3) The author is an experienced and active psychotherapist and philosophically, he would not be expected to promote hypotheses which would counter the effectiveness of direct counseling.

DATA ANALYSIS

Chapter V

INTRODUCTION

The primary objective of the study was to determine whether a social networking model of intervention results in better outcomes among SIDS mothers than the conventional counseling approach.

The data analysis addressed three primary hypotheses:

- (1) MOTHERS IN THE SOCIAL NETWORKING GROUP WILL PERCEIVE THEMSELVES AS HAVING GREATER SOCIAL SUPPORT THAN MOTHERS IN THE CONVENTIONAL GROUP.
- (2) MOTHERS IN THE SOCIAL NETWORKING GROUP WILL HAVE A LESS PROBLEMATIC GRIEF EXPERIENCE THAN MOTHERS IN THE CONVENTIONAL GROUP.
- (3) MOTHERS IN THE SOCIAL NETWORKING GROUP WILL HAVE A LESS PROBLEMATIC BLAME PROCESS THAN MOTHERS IN THE CONVENTIONAL GROUP.

Secondary investigations included correlational analysis of the five dependent variables, analysis of the relationship between perception of support and selected demographic variables and the analysis of "best" and "worst" cases within the networking group, including vignette material.

The statistical tests selected were: the analysis of variance between and within groups for time, treatment and the interaction of treatment with time; tests of simple main effects for the effects of time; t-tests to establish the significance and magnitude of differences over time; t-tests to establish the significance and magnitude of changes observed in both groups and

a series of Pearson Correlation Coefficients for the directional relationships among the five dependent variables.

HYPOTHESIS #1 - MOTHERS IN THE SOCIAL
NETWORKING GROUP WILL PERCEIVE THEMSELVES
AS HAVING GREATER SOCIAL SUPPORT

ANALYSIS OF PERCEPTION OF SOCIAL SUPPORT SCALE

The analysis of variance (ANOVA) in Table 12 indicates that the passage of time, the effects of treatment and the combination of both were all significant regarding the improved perception of social support ($p < .000$, .001 and .000).

TABLE 12. ANALYSIS OF VARIANCE FOR PERCEPTION OF SOCIAL SUPPORT SCORES

| <u>SOURCES OF VARIATION</u> | <u>SS</u> | <u>df</u> | <u>MS</u> | <u>F</u> | <u>SIG.<</u> |
|--------------------------------------|-----------|-----------|-----------|----------|-----------------|
| <u>Between subjects</u> | | | | | |
| Between treatments | 402.34 | 1 | 402.34 | 12.60 | .001 |
| Within treatments | 18512.86 | 58 | 319.19 | | |
| <u>Within Subjects</u> | | | | | |
| Time | 10978.54 | 2 | 5489.27 | 105.65 | .000 |
| Treatment X time | 4824.01 | 2 | 2412.01 | 46.12 | .000 |
| Time X subjects within treatments | 6026.78 | 116 | 51.95 | | |

The data in Table 13 indicates a general decrease in perceived lack of support for both groups, though important differences are evident. The social networking group shows a major reduction in lack of support (increase in perceived support) throughout the course of the study.

The conventional counseling group evidenced a smaller overall decline in non-support, though the trajectory was uneven, marked by a worsening in support between times 2 and 3. Whereas the two groups show fairly similar levels of social support at time 1, prior to intervention, (differences approaching significance, $p < .070$), at the second and third data collection points, the markedly greater improvement in perceived support within the networking group is evident ($p < .000$, $p < .000$).

TABLE 13. MEANS AND STANDARD DEVIATIONS FOR PERCEPTION OF SOCIAL SUPPORT SCALE (percent unsupportive)

| TIME | COMBINED MEAN | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG. < |
|------------|------------------|---------------------------------|--------|-------------------------------|--------|-------|--------|
| | | M | SD | M | SD | | |
| 1 (2 wks.) | 43.899 | 41.333 | 9.098 | 46.4667 | 12.034 | -1.86 | .070 |
| 2 (3 mos.) | 27.033 | 34.8667 | 14.628 | 19.2000 | 8.841 | 5.02 | .000 |
| 3 (6 mos.) | 27.650 | 36.5667 | 15.668 | 18.7333 | 8.998 | 5.41 | .000 |

(df=58)

In addition to the differences observed between the groups at each data collection point, change scores were computed to better assess the magnitude and significance of improvement or deterioration for the particular variable. Thus, the mean change score was calculated by subtracting group means from each other for the duration of the study (time 3 minus time 1) and for the two subdivisions

(time 2 minus time 1, time 3 minus time 2).

Table 14 confirms that the much higher reduction in perceived non-support (actually an increase in perceived support) observed in the social networking group, was significant throughout the course of the study and primarily during time 1 to time 2 ($p < .000$, $p < .000$). This coincided with the networking interventions which also occurred, almost exclusively, from time 1 to time 2. Differences between the groups from three to six months (time 2 - time 3) approached significance ($p < .070$).

TABLE 14. MEANS AND STANDARD DEVIATIONS FOR CHANGE SCORES IN PERCEPTION OF SOCIAL SUPPORT SCALE (reduction in lack of support)

| TIME | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG.< |
|--------------------------|------------------------------|--------|----------------------------|--------|------|-------|
| | M | SD | M | SD | | |
| 2 wks. (1) to 6 mos. (3) | -4.7667 | 12.116 | -27.7333 | 12.301 | 7.29 | .000 |
| 2 wks. (1) to 3 mos. (2) | -6.4667 | 10.766 | -27.2667 | 12.961 | 6.76 | .000 |
| 3 mos. (2) to 6 mos. (3) | 1.7000 | 4.396 | -4.667 | 4.703 | 1.84 | .070 |

(df=58)

A test of simple main effects for TIME, yielded an F of 6.065 ($p < .01$) for the conventional counseling group and an F of 145.787 ($p < .001$) for the networking group. While both statistics attained significance, the magnitude of the reduction of non-support (actually, increased support) for the networking group was almost 25 times that of the conventional group, suggesting that

the effect of time in improving the perception of support was dramatically enhanced by the networking model.

The overall results suggest that mothers in the social networking group perceive themselves as having greater social support, therapy allowing us to reject the null hypothesis and confirm the research hypothesis.

HYPOTHESIS #2 - MOTHERS IN THE SOCIAL
NETWORKING GROUP WILL HAVE A
LESS PROBLEMATIC GRIEF EXPERIENCE

ANALYSIS OF GRIEF SCALE

The analysis of variance presented in Table 15 suggests that the passage of time reduces the intensity of grieving for both groups of high-risk mothers. Treatment alone does not appear to change the grief process ($p < .130$), but the interaction of treatment and time was significant in the reduction of grief for the mothers in the networking group ($p < .000$).

TABLE 15. ANALYSIS OF VARIANCE FOR GRIEF SCALE SCORES (n=60)

| <u>SOURCES OF VARIATION</u> | <u>SS</u> | <u>df</u> | <u>MS</u> | <u>F</u> | <u>SIG. <</u> |
|--------------------------------------|-----------|-----------|-----------|----------|------------------|
| <u>Between subjects</u> | | | | | |
| Between treatments | 5.69 | 1 | 5.69 | 2.42 | .130 |
| Within treatments | 136.62 | 58 | 2.36 | | |
| <u>Within subjects</u> | | | | | |
| Time | 367.41 | 2 | 183.71 | 179.11 | .000 |
| Treatment X time | 16.94 | 2 | 8.47 | 8.26 | .000 |
| Time X subjects within treatments | 118.98 | 116 | 1.03 | | |

The data in Table 16 indicates that grief scores followed a downward trajectory (reduction in grief) for both groups. The greater reduction in grief in the social networking group was significant only at time 3 ($p < .000$), which was 6 months after the loss of a child, suggesting that the network approach required the passage of time for its greater impact.

TABLE 16. MEANS AND STANDARD DEVIATIONS FOR GRIEF SCALE SCORES

| TIME | COMBINED MEAN | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG.< |
|------------|------------------|---------------------------------|-------|-------------------------------|-------|-------|-------|
| | | M | SD | M | SD | | |
| 1 (2 wks.) | 5.0500 | 4.8667 | 1.332 | 5.2333 | 1.040 | -1.19 | .240 |
| 2 (3 mos.) | 2.8167 | 2.9667 | 1.450 | 2.6667 | 1.155 | .89 | .380 |
| 3 (6 mos.) | 1.6000 | 2.1667 | 1.367 | 1.0333 | .809 | 3.91 | .000 |

(df=58)

Table 17 reports the mean change scores, computed in the same manner as the PSS change scores discussed previously. The greater reduction in grief over the course of the study for the networking group ($p<.001$) occurred primarily from time 2 to time 3 ($p<.010$).

TABLE 17. MEANS AND STANDARD DEVIATIONS FOR CHANGE SCORES ON GRIEF SCALE

| TIME | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG.< |
|--------------------------|---------------------------------|-------|-------------------------------|-------|-------|-------|
| | M | SD | M | SD | | |
| 2 wks. (1) to 6 mos. (3) | -2.700 | 1.784 | -4.200 | 1.448 | -3.58 | .001 |
| 2 wks. (1) to 3 mos. (2) | -1.900 | 1.626 | -2.566 | 1.223 | -1.79 | .080 |
| 3 mos. (2) to 6 mos. (3) | -0.800 | 1.349 | -1.633 | 1.033 | -2.69 | .010 |

(df=58)

A test of sample main effects for TIME yielded an F of 56.019 ($p<.001$) for the conventional group and an

F of 130.561 ($p < .001$) for the networking group. While both statistics attained significance, the magnitude of the reduction in grief for the networking group was more than double that of the conventional group, suggesting that the effect of time in reducing grief was markedly augmented by the networking model.

The overall results confirmed that mothers in the social networking group had a less problematic grief experience thereby allowing us to reject the null hypothesis in favor of the research hypothesis.

HYPOTHESIS #3 - MOTHERS IN THE SOCIAL
NETWORKING GROUP WILL HAVE A
LESS PROBLEMATIC BLAME (ATTRIBUTION)

The attribution scale combined scores on three different blaming processes based on the clinical observation that problematic blame whether of oneself, of others or being blamed by others for the infant's death was associated with long term emotional and social distress. The low reliability coefficients previously reported indicated that despite a common clinical and theoretical basis, the three attributional aspects were not measuring a unified construct. Thus, each dimension was treated separately in the data analysis.

ANALYSIS OF SELF BLAME INDEX

The first attributional issue is the mother's reaction of SELF BLAME for the infant's death. Contrary to the literature which associates self-blame with enhanced coping with accidents and misfortune, there appears to be nothing adaptive in feeling responsible for your baby's death, especially when subsequent SIDS are not predictable nor preventable.

The analysis of variance presented in Table 18 suggests that the passage of time is the major force in the lessening of self-blame ($p < .000$) and that time appears to enhance the effects of treatment when they interact ($p < .050$). Treatment alone did not appear to impact positively on

self-blame ($p=.590$).

TABLE 18. ANALYSIS OF VARIANCE FOR SELF-BLAME INDEX SCORES (n=60)

| <u>SOURCES OF VARIATION</u> | <u>SS</u> | <u>df</u> | <u>MS</u> | <u>F</u> | <u>SIG.<</u> |
|--------------------------------------|-----------|-----------|-----------|----------|-----------------|
| <u>Between subjects</u> | | | | | |
| Between treatments | .27 | 1 | .27 | .29 | .590 |
| Within treatments | 54.06 | 58 | .93 | | |
| <u>Within subjects</u> | | | | | |
| Time | 10.68 | 2 | 5.34 | 25.69 | .000 |
| Treatment X time | 1.21 | 2 | .61 | 2.91 | .060 |
| Time X subjects within treatments | 24.11 | 116 | .21 | | |

Table 19 indicates that self-blame decreased for both groups during the course of the study. Mothers in the social networking group felt more self-blame at the outset of the study (prior to intervention), were fairly equal to the other mothers at time 2, and had significantly less self-blame at time 3 ($p<.020$).

TABLE 19. MEANS AND STANDARD DEVIATIONS FOR SELF-BLAME INDEX SCORES

| <u>TIME</u> | <u>COMBINED MEAN</u> | <u>Conventional Group (n=30)</u> | | <u>Networking Group (n=30)</u> | | <u>t</u> | <u>SIG.<</u> |
|-------------|--------------------------|--|-----------|--|-----------|----------|-----------------|
| | | <u>M</u> | <u>SD</u> | <u>M</u> | <u>SD</u> | | |
| 1 (2 wks.) | 2.6167 | 2.2667 | .944 | 2.9667 | 1.048 | -2.69 | .010 |
| 2 (3 mos.) | 1.5833 | 1.6667 | .606 | 1.5000 | .629 | 1.09 | .280 |
| 3 (6 mos.) | 1.2833 | 1.4333 | .568 | 1.1333 | .346 | 2.47 | .020 |

(df=58)

The data in Table 20, based on change scores computed as with the other variables, indicates that the social

networking group showed a greater reduction in self-blame over the duration of the study ($p < .000$) and that this change occurred primarily between times 1 and 2 ($p < .001$).

TABLE 20. MEANS AND STANDARD DEVIATIONS FOR CHANGE SCORES ON SELF-BLAME INDEX

| TIME | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG. < |
|--------------------------|------------------------------|------|----------------------------|-------|------|--------|
| | M | SD | M | SD | | |
| 2 wks. (1) to 6 mos. (3) | .8333 | .834 | 1.8333 | 1.085 | 4.00 | .000 |
| 2 wks. (1) to 3 mos. (2) | .6000 | .770 | 1.4667 | 1.074 | 3.59 | .001 |
| 3 mos. (2) to 6 mos. (3) | .2333 | .430 | .3667 | .490 | 1.12 | .270 |

(df=58)

A test of simple main effects for TIME yielded an F of 16.307 ($p < .001$) for the conventional group and an F of 83.029 ($p < .001$) for the networking group. While both statistics attained significance, the magnitude of the reduction in self-blame for the networking group was more than five times that of the conventional group, suggesting that the effect of time in reducing self-blame was markedly enhanced by the networking model.

ANALYSIS OF BLAME BY OTHERS INDEX

The analysis of variance presented in Table 21 indicates that both the passage of time and treatment interacting with time, are significant in the reduction of the perception of being blamed by others for the infant's

death ($p < .000$). Treatment alone was not significant ($p < .090$).

TABLE 21. ANALYSIS OF VARIANCE FOR BLAME BY OTHERS INDEX SCORES

| SOURCES OF VARIATION | SS | df | MS | F | SIG.< |
|--------------------------------------|--------|-----|-------|-------|-------|
| <u>Between subjects</u> | | | | | |
| Between treatments | 6.42 | 1 | 6.42 | 2.94 | .090 |
| Within treatments | 126.49 | 58 | 2.18 | | |
| <u>Within subjects</u> | | | | | |
| Time | 56.68 | 2 | 28.34 | 85.07 | .000 |
| Treatment X time | 8.01 | 2 | 4.01 | 12.02 | .000 |
| Time X subjects within treatments | 38.64 | 116 | .33 | | |

The data presented in Table 22 show an overall decline in (perceived) blame by others for both groups over the course of the study. Whereas the groups are fairly similar regarding this variable at time 1, the networking group reported less blame by others at time 2 ($p < .020$) and at time 3 ($p < .040$).

TABLE 22. MEANS AND STANDARD DEVIATIONS FOR BLAME BY OTHERS INDEX SCORES

| TIME | COMBINED MEAN | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG.< |
|------------|------------------|---------------------------------|-------|-------------------------------|-------|------|-------|
| | | M | SD | M | SD | | |
| 1 (2 wks.) | 2.2498 | 2.3333 | 1.124 | 2.1667 | 1.147 | .57 | .570 |
| 2 (3 mos.) | 1.8500 | 2.1333 | .973 | 1.5667 | .774 | 2.50 | .020 |
| 3 (6 mos.) | 1.6667 | 1.8667 | .819 | 1.4667 | .629 | 2.12 | .040 |

(df=58)

Table 23 presents change scores (computed as previously described) indicating that the amount of reduction in blame by others over the duration of the study was not statistically significant ($p < .240$), despite a greater reduction in blame by others for the networking group between time 1 and time 2 ($p < .030$).

TABLE 23. MEANS AND STANDARD DEVIATIONS FOR CHANGE SCORES ON BLAME BY OTHERS INDEX

| TIME | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG. < |
|--------------------------|------------------------------|------|----------------------------|------|------|--------|
| | M | SD | M | SD | | |
| 2 wks. (1) to 6 mos. (3) | -.4667 | .681 | -.7000 | .837 | 1.18 | .240 |
| 2 wks. (1) to 3 mos. (2) | -.2000 | .484 | -.6000 | .814 | 2.31 | .030 |
| 3 mos. (2) to 6 mos. (3) | -.2667 | .521 | -.1000 | .403 | 1.39 | .170 |

(df=58)

A test of simple main effects for TIME yielded an F of 7.857 ($p < .001$) for the conventional group and an F of 20.476 ($p < .000$) for the networking group. While both statistics attained significance, the magnitude of the reduction of (perceived) blame by others was nearly three times that of the conventional group, suggesting that the effect of time in reducing blame by others was greatly enhanced by the networking approach.

ANALYSIS OF BLAMING OTHERS INDEX

The analysis of variance presented by Table 24 indicates that primarily the passage of time reduced the blaming of others ($p < .000$) and that the interaction of time and treatment was also statistically significant ($p < .020$). Treatment alone did not account for a significant reduction in blaming others ($p < .860$).

TABLE 24. ANALYSIS OF VARIANCE FOR BLAMING OTHERS INDEX SCORES

| SOURCES OF VARIATION | SS | df | MS | F | SIG.< |
|--------------------------------------|-------|-----|------|-------|-------|
| <u>Between subjects</u> | | | | | |
| Between treatments | .05 | 1 | .05 | .03 | .860 |
| Within treatments | 95.34 | 58 | 1.64 | | |
| <u>Within subjects</u> | | | | | |
| Time | 2.41 | 2 | 1.21 | 12.24 | .000 |
| Treatment X time | .83 | 2 | .42 | 4.23 | .020 |
| Time X subjects within treatments | 11.42 | 116 | .10 | | |

The data presented in Table 25 indicates a general reduction in blaming others for the infant's death over the course of the study, though the mothers in the conventional counseling group did show a slight increase in this variable at time 3. Reported differences between the two groups at all three data collection points were not statistically significant.

TABLE 25. MEANS AND STANDARD DEVIATIONS FOR BLAMING OTHERS INDEX SCORES

| TIME | COMBINED MEAN | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG.< |
|------------|------------------|---------------------------------|------|-------------------------------|------|-------|-------|
| | | M | SD | M | SD | | |
| 1 (2 wks.) | 1.7833 | 1.6333 | .890 | 1.9333 | .944 | -1.27 | .210 |
| 2 (3 mos.) | 1.5333 | 1.5000 | .777 | 1.5667 | .774 | -0.33 | .740 |
| 3 (6 mos.) | 1.4666 | 1.5333 | .776 | 1.4000 | .621 | .73 | .470 |

(df=58)

Table 26 reports change scores (computed as before) over the course of the study and within each time period. The greater reduction in blaming others within the social networking group was noted from the beginning to the end of the study ($p < .010$), and it occurred primarily between times 2 and 3 ($p < .010$). The differences in the amount of reduced blaming of others was not significant between time 1 to time 2.

TABLE 26. MEANS AND STANDARD DEVIATIONS FOR CHANGE SCORES ON BLAMING OTHERS INDEX

| TIME | Conventional Group (n=30) | | Networking Group (n=30) | | t | SIG.< |
|--------------------------|---------------------------------|------|-------------------------------|------|------|-------|
| | M | SD | M | SD | | |
| 2 wks. (1) to 6 mos. (3) | .1000 | .403 | .5333 | .776 | 2.71 | .010 |
| 2 wks. (1) to 3 mos. (2) | .1333 | .346 | .3667 | .718 | 1.60 | .120 |
| 3 mos. (2) to 6 mos. (3) | .0333 | .183 | .1667 | .379 | 2.60 | .010 |

(df=58)

A test of simple main effects for TIME yielded an F of 17.153 ($p < .001$) for the networking group. The findings suggest that the passage of time for the conventional group does not have a significant effect on blaming others, whereas for the networking group, it is both significant and augmented by the approach.

The overall results indicate that mothers in the social networking group had less self-blame, less (perceived) blame by others and blamed others less thereby allowing us to reject the null hypothesis and confirm the research hypothesis.

CORRELATIONAL ANALYSIS OF DEPENDENT VARIABLES

An analysis of correlations of CHANGE SCORES based on mean differences between time 1 and time 3 was conducted by computing Pearson coefficients for all dependent variables. The correlation matrix is presented below:

TABLE 27. COEFFICIENTS FOR CHANGE SCORES FOR DEPENDENT VARIABLES (n=60)

| | Increased Social Support | Decreased Grief | Decreased Self-Blame | Decreased Blame by Others | Decreased Blaming Others |
|------------------------------|-----------------------------|--------------------|-------------------------|---------------------------------|--------------------------------|
| Increased Social Support | 1.000 | .4300*** | .4284*** | .0849 | .2787* |
| Decreased Grief | .4300*** | 1.0000 | .4217*** | .1835 | -.1383 |
| Decreased Self- Blame | .4284*** | .4217*** | 1.0000 | -.1770 | .2082 |
| Decreased Blame by Others | .0849 | .1835 | -.1770 | 1.0000 | .0312 |
| Decreased Blaming Others | .2787* | -.1383 | .2082 | .0312 | 1.0000 |

(* $p < .05$, *** $p < .001$)

The above data indicates positive significant correlations between increased social support and decreased self-blame; between increased support and decreased grief and between decreased self-blame and decreased grief ($p < .001$). At the .05 level of significance, improvement in social support is positively correlated with improvement in blaming others for the infant's death.

Table 28 presents a summary of the test of simple main effects for TIME reported previously in this chapter under the appropriate variable. The findings suggest that for both treatment approaches, the passage of time was significant in the improvement in perceived support and in the reduction of grief, self-blame and blame by others (blaming others was not statistically significant for the conventional group). In addition, the F ratios indicate the magnitude of the differences between the two treatment groups with the social networking group showing markedly, and in some instances, dramatically enhanced effects via the interaction with time.

TABLE 28. TEST OF SIMPLE MAIN EFFECTS FOR TIME (n=60)

| VARIABLE | Conventional Group | Networking Group |
|-----------------|-----------------------|---------------------|
| | F | F |
| Social Support | 6.065** | 147.787*** |
| Grief | 56.019*** | 130.561*** |
| Self-Blame | 16.307*** | 83.029*** |
| Blame by Others | 7.857*** | 20.476*** |
| Blaming Others | 1.115 | 17.153*** |

(df=2, 120) **p<.01, ***p<.001

ANALYSIS OF DEMOGRAPHIC VARIABLES

Additional investigation was undertaken to determine whether any of the major demographic variables (presence/absence of surviving siblings, race, religion, socioeconomic status, marital status or maternal age) were impacting on the mother's perception of social support.

(1) PRESENCE/ABSENCE OF SURVIVING SIBLINGS

t-test analysis of the data in Table 29 indicates that there is no significant difference in perception of social support regardless of whether the bereaved mother had surviving children ($p < .192$).

TABLE 29. MEAN AND STANDARD DEVIATION PSS SCORES ACCORDING TO PRESENCE OR ABSENCE OF SURVIVING SIBLINGS (n=60)

| GROUP | N | MEAN | SD | t-value | df | SIG.< |
|---------|----|-------|-------|---------|----|-------|
| SIBS | 32 | 45.59 | 12.06 | 1.32 | 58 | .192 |
| NO SIBS | 28 | 41.96 | 9.19 | | | |

(2) RACE (Maternal)

The data presented in Table 30 indicates the mean Perception of Social Support Scale scores for various racial groupings of respondents.

TABLE 30. MEAN AND STANDARD DEVIATION PSS SCORES ACCORDING TO MATERNAL RACE (n=60)

| Group | N | MEAN | SD |
|----------|----|-------|-------|
| Black | 37 | 44.78 | 11.10 |
| Hispanic | 8 | 39.12 | 9.10 |
| Cauc. | 14 | 44.35 | 11.64 |
| Other | 1 | 43.00 | - |

The analysis of variance indicated that differences in maternal race were not significantly related to perception of social support.

(3) RELIGION (Maternal)

The data presented in Table 31 indicates the mean PSS scale scores for various religious groupings of respondents.

TABLE 31. MEAN AND STANDARD DEVIATION PSS SCORES ACCORDING TO MATERNAL RELIGION (n=60)

| RELIGION | N | MEAN | SD |
|------------|----|-------|--------|
| Protestant | 37 | 44.64 | 11.066 |
| Catholic | 21 | 42.04 | 10.832 |
| Jewish | 1 | 56.00 | - |
| Other | 1 | 43.00 | - |

The analysis of variance indicated that differences in maternal religion were not significantly related to perception of social support.

(4) SOCIOECONOMIC STATUS

The analysis is based on four SES levels designated by Hess and Shipman (1965): (1) professional/managerial, (2) skilled blue collar, (3) semi-skilled/unskilled, and (4) AFDC.

Table 32 presents the mean and standard deviation PSSS scores according to socioeconomic level.

TABLE 32. MEAN AND STANDARD DEVIATION PERCEPTION OF SOCIAL SUPPORT SCORES AND SOCIOECONOMIC STATUS (n=60)

| SES | N | MEAN | SD |
|-----|----|-------|-------|
| I | 6 | 38.50 | 5.54 |
| II | 22 | 45.27 | 11.48 |
| III | 9 | 47.44 | 13.96 |
| IV | 23 | 42.60 | 9.86 |

The analysis of variance indicated that differences in socioeconomic status were not significantly related to perception of social support.

(5) MARITAL STATUS

Table 33 presents the mean and standard deviation scores for perception of social support according to marital status.

TABLE 33. MEAN AND STANDARD DEVIATION PSS SCORES AND MARITAL STATUS
(n=60)

| MARITAL STATUS | N | MEAN | SD |
|----------------|----|-------|-------|
| Married | 23 | 43.78 | 11.43 |
| Divorced | 2 | 48.00 | 15.55 |
| Separated | 1 | 42.00 | - |
| Widowed | - | - | - |
| Unmarried | 34 | 43.79 | 10.78 |

The analysis of variance indicated that differences in marital status were not significantly related to perception of social support.

(6) MATERNAL AGE

Pearson correlation coefficient was calculated to determine the co-variance and strength of relationship, indicating that maternal age does not influence perception of social support ($p < .343$).

The additional analyses examined the hypotheses that six demographic variables would affect the perception of social support. The findings indicated that the null hypotheses were supported with each variable and that perception of social support was unaffected.

ANALYSIS OF ANECDOTAL MATERIAL

The final section of the data analysis builds on the previous findings which depicted the social networking model as being associated with more positive coping. It was considered desirable to explore, with anecdotal detail, the therapeutic mechanisms and family characteristics which exemplified both optimal responses as well as lack of improvement.

Initial efforts to locate cases which showed optimal or poor outcomes across all dependent variables (perception of social support, grief, self-blame, blaming others and being blamed by others) was unsuccessful as no cases met those criteria. It was therefore decided that the selection of "best" and "worst" cases should be based primarily on Perception of Social Support (PSS) scale scores since social support was the key element in the development of the model and its implementation.

Since PSS scores were computed based on the percentage of network members perceived as unsupportive, the best and worst cases were defined as showing the greatest and least improvement over the six-month duration of the study.

The positive or negative change was therefore calculated via ratios based on the subtraction of percentages

at time 3 from those of time 1. For example, case number 2 showed a -42.00 reduction ($49.00 - 7.00$) in lack of support (actually, increased support) with a calculated ratio of change of .86. Using this formula, five cases with highest and five cases with lowest ratios were located ($n=10$). The mean ratio of change for the five best cases was -.86 (actually .86 improvement) and for the five worst -.24 (.24 improvement).

The mean change scores for the remaining dependent variables and the totals for the demographic variables are presented for the best and worst groups in Tables 34 and 35.

The data indicates that for most variables (apart from the criterion of social support--PSS) the two groups are similar with several important exceptions. The worst outcome cases were more likely to be employed and married, and experienced almost twice the number of stressors as the best cases. In this latter area, all of the worst outcome mothers noted psychological/psychiatric conditions as contrasted with only two of the best outcome cases.

TABLE 34. MEAN CHANGE SCORES FOR GRIEF AND BLAME VARIABLES
FOR "BEST" AND "WORST" CASES (n=10)

| VARIABLE and TIME | BEST (n=5) | WORST (n=5) |
|------------------------|------------|-------------|
| <u>Grief</u> | | |
| T1 | 5.4 | 4.8 |
| T2 | 2.8 | 3.6 |
| T3 | .8 | 1.8 |
| <u>Self-Blame</u> | | |
| T1 | 2.6 | 2.4 |
| T2 | 1.8 | 1.6 |
| T3 | 1.2 | 1.2 |
| <u>Blame by Others</u> | | |
| T1 | 2.2 | 2.6 |
| T2 | 1.4 | 2.4 |
| T3 | 1.0 | 2.2 |
| <u>Blaming Others</u> | | |
| T1 | 1.8 | 2.2 |
| T2 | 1.6 | 2.0 |
| T3 | 1.4 | 1.6 |

TABLE 35. TOTALS FOR SELECTED DEMOGRAPHIC VARIABLES FOR
"BEST" AND "WORST" CASES (n=10)

| <u>VARIABLE</u> | <u>BEST (n=5)</u> | <u>WORST (n=5)</u> |
|-----------------------|-------------------|--------------------|
| <u>MARITAL STATUS</u> | | |
| Married | 1 | 4 |
| Single | 4 | 1 |
| <u>EMPLOYMENT</u> | | |
| Employed | 2 | 4 |
| Unemployed | 3 | 1 |
| <u>Stress Areas</u> | | |
| Psychiatric | 2 | 5 |
| Social | 3 | 4 |
| Medical | 1 | 2 |
| Housing | 2 | 1 |
| Economic | - | 2 |
| Work | 1 | 2 |
| Legal | 1 | 1 |
| TOTAL (Stress) | 10 | 17 |

Table 36 presents the means for all interventions for both groups. The data suggests that the worst outcome cases had almost twice the telephone contact with the SIDS counselor, more likelihood of contact with a public health nurse, less contact with and literature sent to friends and professionals and five times the number of referrals to other agencies and services.

TABLE 36. MEANS FOR ALL INTERVENTIONS FOR "BEST" & "WORST" CASES

| INTERVENTION AND FOCUS | BEST (n=5) | WORST (n=5) |
|------------------------|------------|-------------|
| <u>MOTHER</u> | | |
| Interview | 2.6 | 2.4 |
| Phone call | 1.6 | 2.8 |
| Literature | 1.0 | 1.0 |
| Nurse visit | .6 | 1.2 |
| Parent group | .4 | .8 |
| Referral | .4 | 2.0 |
| <u>KIN</u> | | |
| Interview | .8 | 1.0 |
| Phone call | 2.0 | 1.6 |
| Literature | 3.0 | 3.0 |
| <u>FRIENDS</u> | | |
| Interview | .2 | - |
| Phone call | 1.0 | .6 |
| Literature | 2.4 | 1.4 |
| <u>PROFESSIONALS</u> | | |
| Interview | - | - |
| Phone call | 1.4 | .4 |
| Literature | 1.6 | .4 |

Case vignettes for the worst and best outcome groups described previously are presented:

THE "WORST" CASES

CASE #18 - This married mother worked as a waitress and noted that her struggle with recurrent depressions was seriously worsened by the baby's death, requiring a new round of anti-depressant and anti-anxiety medication. Although her work relationships were marginal (there were no long-term close friendships), she felt very

rejected when her grief and depression kept her home for two weeks and no co-workers visited. She wondered whether they were secretly blaming her for the baby's death and deciding that they were, she stopped socializing with them and drew closer to her husband and aunt.

CASE #34 - This single parent of three was supported by public assistance and lived in a tenement used as a "crack den" by local hoodlums. She was infuriated by this, but felt helpless to eradicate the problem or to move. Also, she felt that the landlord had not provided enough heat and she implicated this in her baby's death. In terms of economic stress, she had recently been accused of defrauding Con Edison and the resulting settlement further reduced her stipend.

Her social difficulties included three out of wedlock children via two fathers who both abandoned her, with subsequent rejection by most of her family. She also acknowledged difficulty in disciplining her children, noting that neighbors confronted her as being "too strict."

Psychiatrically, this mother had at least a ten-year history of alcohol abuse which was exacerbated by the SIDS death. She added that she "wasn't interested in other people's problems," as a reason for not attending Alcoholics Anonymous.

CASE #48 - This married mother of two struggled initially with marked self-blame which appeared to respond to cognitive antidotes aimed at the non-predictability and non-preventability of SIDS. She also felt that emergency and health personnel were not diligent enough due to her ethnicity.

Of Middle Eastern background, this mother worked in a grocery store with her husband, spending very long hours away from family and friends of her own culture and feeling uncomfortable with the "American" customers. Thus, because of the lack of a more personal relationship with the clientele, her work situation afforded her virtually no empathic exchanges nor validation of her worth.

Shortly after her son's death, she was hospitalized due to status asthmaticus, the condition reaching a severity she had not known since childhood. Her poor health limited her stamina in the store and she noted much guilt over not helping her husband overcome his financial problems. She noted that three months before the baby died, she was taking anti-depressant medication, the third time since coming to the U.S., fifteen years before.

CASE #52 - This married mother with one surviving sibling had been struggling with paranoid schizophrenia for the past six years. She initially felt intense self-blame

along with perceptions of severe blame from others. She voiced equally pronounced feelings of blame towards specific personnel and towards the health care system in the U.S.

This woman had been hospitalized twice and was currently maintained via anti-psychotic medication and monthly psychotherapy. She did not believe the Medical Examiner's findings, suspecting collusion between the private pediatrician and the pathologist. She also could not easily accept condolences thinking "they just want to see how upset I am and whether I might have done something wrong." She also had a controlled seizure disorder since adolescence which she feared would resurface during her mourning. Given the above, she chose to seclude herself at home for eight weeks and was eventually able to return to her job.

She was also in the middle of a malpractice suit against her dentist and lamented the chronic pain which she attributed to his ineptitude.

Work was P/T sales for Avon, more to occupy her time than to contribute to the family finances. She felt "distant" with her husband, but was especially close with her mother, brother and uncle.

The "best" cases (actually the best of the best), exemplify those aspects of the networking approach which

appear associated with its effectiveness.

THE "BEST" CASES

CASE #2 - This single working mother of two was preoccupied with a discrimination lawsuit which she had filed against her employer (Health and Hospitals Corporation). Following the loss of her son, her co-workers eventually rallied to her support, helping to suppress her fear that ER treatment was limited due to her lawsuit.

This mother acknowledged a chronic suspiciousness, which in the case of former boyfriends resulted in intense jealousy and subsequent termination of the relationship. In many of her family and social contacts she felt "taken advantage of" and victimized by merchants and others, resulting in a self-description of having "bad nerves." Nonetheless, her social network responded very positively and sympathetically despite her personality difficulties.

CASE #4 - This single older adolescent mother living with her parents and grandmother, reported no stress areas in her life with correspondingly low blame scores and rapid, sustained reduction in grief over the six-month period. Her pregnancy and childcare responsibilities had isolated her from previous friendships and her family's relocation impacted on other supportive relationships from the "old neighborhood." She also perceived several

relatives as alienated due to the out of wedlock pregnancy, though these and former friends became highly supportive over time.

CASE #8 - This married mother of two indicated that her colitis had again flared shortly after the crib death. Her husband, mother-in-law and several relatives blamed her for the infant's death and she reluctantly revealed a prior abortion as her own reason for this punishment. In addition, she felt that the EMS ambulance was too slow in responding, resulting in the loss of her child. All of this translated into higher than average scores in all three blame areas and the recurrence of a medical problem which she had always associated with emotional stress. A family network session and phone calls to key relatives resulted in a more caring response to this rather unemotional, reserved woman.

CASE #20 - This single unemployed parent of four was initially the target of numerous accusations concerning her son's death, beginning with her boyfriend (baby's father), her mother, sisters and uncle. She also perceived hostile responses from the emergency personnel, the M.E. staff and the funeral director. Some of this she attributed to the placement of her children in foster care two years before due to charges of neglect. Her housing condition was still overcrowded and not consid-

ered appropriate for an infant. Nonetheless, her family and kin were able to respond positively once the explanation for SIDS was offered emphatically at a family meeting by the baby's pediatrician (with SIDS counselor consultation). The support offered by her network during her grief appeared to extend itself to helping the mother and her children, in general.

CASE #40 - This single unemployed mother was initially overwhelmed by her grieving, never having personally experienced a death among her family or friends. She lived with another woman and her two children and after the baby's death was "considered a curse" and asked to move. Her new apartment was quite a distance from her familiar neighborhood, since she viewed this as only a temporary relocation. The result was very intense feelings of isolation and loneliness following this tragedy. Also, she had just finished a training program in cosmetology but as yet was still unemployed two months after graduation.

A shy and unassuming woman, she seemed unable to make new acquaintances and did not mention to neighbors or others that she had recently been traumatized. She was able, instead, to make use of the SIDS counselor, parent group and Compassionate Friends Program where she felt a greater sense of belonging and less "cursed."

SUMMARY

The social networking model of intervention with SIDS families, developed as part of this dissertation, was tested using a comparative treatment design against the existing bereavement counseling approach.

The three primary hypotheses were:

- (1) MOTHERS IN THE SOCIAL NETWORKING GROUP WOULD PERCEIVE THEMSELVES AS HAVING GREATER SOCIAL SUPPORT THAN MOTHERS IN THE CONVENTIONAL GROUP.
- (2) MOTHERS IN THE SOCIAL NETWORKING GROUP WOULD HAVE A LESS PROBLEMATIC GRIEF EXPERIENCE THAN MOTHERS IN THE CONVENTIONAL GROUP.
- (3) MOTHERS IN THE SOCIAL NETWORKING GROUP WOULD HAVE A LESS PROBLEMATIC BLAME EXPERIENCE THAN MOTHERS IN THE CONVENTIONAL GROUP.

SOCIAL SUPPORT

The data indicated that the passage of time, the social networking approach and the interaction of both were significant in the perception of increased social support ($p < .000$, $p < .001$ and $p < .000$ respectively).

The findings also indicate that the perception of support increased for both groups, though the networking group showed a greater and more sustained improvement ($p < .000$).

The greatest improvement in perceived support coincided with the social networking interventions which occurred during time 1 and time 2.

Additional analysis indicated that the mothers' perception of social support was not influenced by the

major demographic variables: maternal age, race, religion, marital and socioeconomic status and the presence of surviving siblings.

The overall results support the research hypothesis and allow us to reject the null hypothesis.

GRIEF

The data indicated that the passage of time and the interaction of time and treatment were significant in the reduction of grief symptoms ($p < .000$, $p < .000$), though treatment alone was not.

The findings also indicated that, consistent with numerous bereavement studies, grief decreased for both groups, though the networking group experienced the greater reduction in grief, which occurred primarily from time 2 to time 3.

The overall results support the research hypothesis and allow us to reject the null hypothesis.

SELF-BLAME

The data indicated that the passage of time ($p = .000$) and, to a lesser extent, the interaction of treatment with time ($p < .060$) were significant in the reduction of self-blame.

The findings also indicated that self-blame decreased for both groups, with the greater reductions for the networking group occurring between times 1 and 2, and

the differences between the groups most evident at time 3.

The overall results support the research hypothesis and allow us to reject the null hypothesis.

BLAME BY OTHERS

The data indicated that the passage of time and the interaction of treatment with time were significant in the reduction of perceived blame by others ($p < .000$, $p < .000$). Treatment alone did not appear to have a significant impact.

The findings also indicated that while both groups showed a decrease in perceived blame by others over time, the networking group showed a greater reduction during time 1 and 2, with significantly lower scores at time 2 and 3.

The overall results support the research hypothesis and allow us to reject the null hypothesis.

BLAMING OTHERS

The data indicated that the passage of time and the interaction of treatment with time were both significant in the reduction of blaming others ($p < .000$, $p < .020$). Treatment alone did not appear to have a significant impact.

The findings also indicate that blaming others decreased for both groups with the networking group showing a greater reduction in blaming, particularly between time 2 and

time 3. Although the networking group began with a higher score and finished with a lower score, the differences between the two groups over time did not achieve statistical significance.

The overall results support the research hypothesis and allow us to reject the null hypothesis.

ADDITIONAL ANALYSES

Correlational analysis of the changes in dependent variable scores indicated significant correlations between: (1) increased social support and reduced grief, (2) increased social support and reduced self-blame, and (3) reduced self-blame and reduced grief ($p < .001$). A relationship was also observed between increased social support and reduced blaming of others ($p < .05$).

A test of simple main effects for TIME highlighted the markedly, sometimes dramatically enhancing effects of the social networking approach on the passage of time in increasing the perception of support and reducing grief and blame.

Finally, to better understand the therapeutic mechanisms associated with the social networking model, a sample of "best" and "worst" outcome cases ($n=10$) were selected and analyzed according to grief and blame scores, demographic variables and interventions. The "worst"

cases differed in that they were more likely to be married and employed, with psychiatric conditions observed in all five cases and social/relationship difficulties reported in most. In addition, the worst outcome cases had more contact with a SIDS counselor and public health nurse, and more referrals to other services and agencies. Thus, while the stressors clearly differentiated the two groups, the worst cases had ostensibly more stress-buffering factors in terms of marital/work status and number of interventions. The interpretation of these findings will be discussed in the next chapter.

DISCUSSION

CHAPTER VI

The previously presented findings confirmed the primary hypotheses that SIDS mothers in the social networking group perceived greater support and experienced greater reductions in grief and blame. This chapter will discuss the interpretations of the data, as well as its generalizability and limitations. Future research issues and implications for professional social work are also reviewed.

INTERPRETATION OF THE FINDINGS

The passage of time in this six-month study emerged as a powerful force in the improvement of perceived social support and in the reduction of grief, self-blame, blaming others and perceived blame by others, for both groups of bereaved mothers. This finding, in terms of grief reduction is consistent with the review of bereavement studies (Institute of Medicine, 1984) and supports the portrayal of time as reducing the intensity of grief and the "state of crisis" in the theoretical and clinical literatures. In addition, the finding suggests that where "high-risk" bereaved mothers are defined by a relative lack of social support, the usual downward trajectory for grief symptoms occurs, contrary to expectation, at least during a six-month period.

The observed reduction in self-blame over time requires clarification in view of other findings which document the long term (3 yrs.) duration of maternal guilt following a SIDS loss (DeFrain et al., 1982; Rubin, 1985). Thus, the relative decrease in self-blame in this study may not obviate its damaging persistence over a period of years and even if self-blame would be considered completely suppressed in this research, the brief duration of the study could not be offered as having predictive value for the long term.

Another explanation for this hypothesizes an important conceptual and, ultimately, clinical distinction. Self-blame for the infant's death was assessed within the context of other blaming processes and was probably interpreted by the mother in terms of acts of commission or omission directly impacting on the baby's survival. This process appeared very amenable to "cognitive antidotes" which emphasized the lack of predictability/preventability, as well as the rapidity of the infant's death. The mental and physical relief which mothers experienced in response to such explanations and reassurances was strikingly visible during interviews. Guilt, on the other hand, may derive from a deeper sense of responsibility and punishment, perhaps experienced by the mother as Divine retribution for previous misdeeds.

Occasionally, mothers would verbalize a connection between a voluntary abortion years before and the death of their baby, currently. It is this type of self-blame which may remain unspoken and persist as a source of emotional distress, unalleviated by explanations about SIDS or even more intensive psychotherapeutic efforts. A similar distinction was presented by Miles (1988), who discussed various kinds of guilt following a SIDS. She contrasted death causation guilt (based on rational or irrational scientific, medical evidence) with moral guilt, childrearing guilt, grief guilt and survivor's guilt.

The findings also indicate that (with the exception of perceived increases in support) the social networking model was responsible for the greater reduction of grief and blaming, only in its interaction with the passing of time. The networking treatment alone was no more effective than the conventional counseling approach in decreasing those sources of distress. Rather, it would appear that the networking approach impacts directly on the mother's perception of social support which functions as a mediating or intervening variable to decrease dysfunctional responses.

This interpretation thus implies a sequential model of therapeutic impact which proposes that the SIDS counselor's networking efforts, which occurred almost exclu-

sively during time 1 to time 2, directly resulted in a dramatically improved perception of support (simple main effects F ratio was 25 times higher than conventional group). The greater reduction in self-blame and perceived blame by others during this same time period (t-tests of change scores) suggests that the mother's internal attributions of causality were mediated by the disavowing messages which she perceived in her social network. Alternately, one might consider a more complex interaction based on the reminder that the two approaches were not mutually exclusive modalities, but rather the networking model included all of the direct counseling activities of the conventional model. Thus, one might speculate that the initial tendency toward self-blame was countered by network members who challenged that premise and supported the mother's innocence and self-worth, which (when professed openly by the mother) allowed for further network validation and support. This concept of the reciprocally reinforcing or damaging relationship between the individual and her social system is also supported by the anecdotal material to be reviewed later.

Further evidence of a sequential mechanism may be seen in the findings which indicate that the greater reduction in grief and blaming others within the networking group occurred primarily between times 2 and 3. In terms

of grief, one may speculate that unlike the cognitively-based processes of self-blame and perceived blame by others, the emotional and physiologic aspects of grief (which largely comprised the Grief Scale) require more time to subside. Again, the relatively brief duration of the study may confound this observation. In addition, the findings support those cognitive theorists who propose that changes in attribution precede changes in felt and expressed emotion. Thus, the noted reduction in self-blame during time 1 to time 2 enabled the greater reduction in grief distress at a later point in time.

In terms of blaming others, this process seemed least affected by the passage of time and the networking approach, although a greater reduction in this variable between times 2 and 3 suggests several explanations. Thus, unlike other reactions, one might speculate that anger is a more enduring, longer-tolerated emotional state and that its amelioration would take longer. Also, it is conceivable that this kind of blame may be supported by key network members when the object of blame is the pediatrician who "missed" the impending tragedy or the emergency personnel who responded "too slowly." Blaming others, especially professionals, for the baby's death has periodically led to lawsuits and clinically has been observed to persist in some families for years after

the death.

In addition to the proposed sequence of change just described, the data also indicates the relational strength of the variables. Thus, improvements in the perception of social support are most strongly correlated with reductions in self-blame and grief over the course of the study (Pearson - $p < .001$, $p < .001$).

This finding is also consistent with several SIDS studies which note the importance of social support in coping with the loss of an infant (Dyregrov and Matthiesen, 1987a, 1987b). Similarly, Crichton (1983) observed that social support helped to ameliorate grief and Tudehope, et al. (1986) reported a negative correlation between social support and pathologic grief. The positive impact of network support on self-blame was also evident in families studied by Pflaumer (1983). It should be noted that whereas in the previous SIDS studies social support was naturally available and correlated with positive outcomes, in this research the change in perceived support was induced by the treatment approach. ;

The mechanisms by which perceived support lessens

grief and blame processes probably operate on both general and specific levels. On a general level, perceiving support and care would engender a feeling of belonging and a sense of worth, thereby addressing the need to reconnect and dispelling the self-castigation. On a specific level, the support and guidance of network members can inform and model grief and mourning responses, and counter the self-blame attributions with SIDS information and other explanations of external causality.

In summation, perceived support generated by networking interventions functioned as a mediating and stress-buffering variable in this study, a finding consistent with the portrayal of social support in the health and mental health literature.

Given the greater effectiveness of the social networking model, the study also attempted to clarify the qualitative aspects of its efficacy by exploring vignette and anecdotal material. By comparing several of the best and worst cases within the networking group, it was felt that one could highlight the method in optimal situations, as well as observe the factors which minimized its impact.

The group comparisons and case vignettes indicated that the worst outcome cases had more psychiatric and social stressors than the best cases. The case material indicated that the responsiveness of the bereaved mother and her social network to networking intervention was

a function of person-network "fit." In the worst cases, for example, the mother's personality, affective or psychotic disorder either alienated network members or led her to avoidance and seclusion. Depressions, paranoid ideation and substance abuse problems appear to operate in this manner, though one must assume that it is the interactive quality between mother and network, the interface between person and environment, that accounts for the difference, rather than focusing on deficits in either. Thus, in one of the poor outcome cases, the lack of social support and the lack of response to networking efforts seemed related to the mother's disavowal of SIDS as an explanation for the infant's death. This seemed to confuse family and friends, perhaps aroused suspicion and also allowed opportunity for speculating and theorizing by network members. This process resulted in many collisions and finally, the withdrawal by the mother. Perhaps a different network would have responded more tactfully and supportively.

Indeed, among the five "best" cases, there also appeared depressive and paranoid functioning (albeit to a lesser degree) and stigmatizing situations, yet those networks and mothers achieved a wonderfully supportive and sustained fit.

This issue, then, is certainly an area for further

analysis and investigation so as to enable the clinician to employ networking methods in the most appropriate situations, and to search for other approaches for the less promising scenarios.

LIMITATIONS AND FUTURE RESEARCH

The sample of SIDS families who participated in this study were demographically similar to SIDS families described in the majority of epidemiologic research. However, the focus on "high risk" mothers might render the networking approach more appropriate to these cases, while other SIDS families could perceive the approach as unnecessary or intrusive. In addition, the sample was relatively small for a comparative design (n=60) and replication with a larger group would be useful.

Other methodologic issues include: the need for long-term research designs to better assess the duration of changes observed, the clarification of the relationship between the perception vs. an objective measure of social support, the importance of developing or locating a measure of role functioning, the overall need for more reliable measures and finally, an attempt to separate the effects of networking alone, apart from its combination with the conventional methods.

As with other treatment approaches, further research should address the parsimony of the model, any risks

or negative consequences associated with its use, and the differential application.

IMPLICATIONS FOR SOCIAL WORK

Model development as a form of practice research has been described as the most appropriate research methodology for social work (Thomas, 1980). This dissertation addressed our profession's paramount concern with the integration of research and clinical services. The study reflected social work's willingness to explore alternate ways of serving a newly identified population in need. With the New York City morgue as the practice setting, the unspeakable tragedy of a baby's death and the limitations of the existing literature and practice approaches in bereavement, the researcher was presented with both challenge and opportunity.

The networking model and the study findings also have major implications for social work's identification with crisis theory and intervention. Based on ecological and systems concepts, the social networking approach modified the unit of attention, the objectives of treatment and, most significantly, the role of the clinician. In contrast with the primary emphasis on direct counseling provided by the practitioner, the new model casts the clinician in the role of orchestrator of network members and resources. With the dual strategies of op-

timalizing the person-network fit or creating supportive networks and providing linkage, the practitioner can fulfill social work's historic focus on person-in-environment.

CONCLUSION

This dissertation study set out to build a better mousetrap. Searching for concepts and empirical data in the literature to guide clinical efforts with SIDS families, it became apparent that traditional crisis intervention and bereavement theory were insufficient and not validated.

Using a modified research and development approach, a practice model was designed which highlighted the pivotal role of social support in coping with life crises. This and other consensus findings were incorporated into the social networking model which emphasized the sensitizing and educating of the existing network or the creation of, and linkage to, an artificial support network; both to help the bereaved accomplish the key coping tasks associated with an infant's death due to SIDS.

The testing of the model using a comparative treatment design, involved methodologic compromises to address the needs of acutely bereaved persons. New, brief, less emotionally and cognitively taxing instruments had to be constructed, the sample was relatively small and the

duration of the study couldn't capture the lengthier aspects of mourning and coping.

Nonetheless, this study has demonstrated that the combination of social networking efforts and conventional bereavement counseling is more effective than counseling alone. The findings and the model may be applicable with many of the 7,000 annual SIDS deaths across the country, and the study has broadened crisis theory in terms of the role of the clinician.

I close with a tribute to the deceased infants and to all those who cherish them:

And can it be that in a world so full and busy, the loss of one weak creature makes a void in any heart, so wide and deep that nothing but the width and depth of vast eternity can fill it up.

- Charles Dickens
Dombey and Sons

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APPENDIX ASummary of the Intervention Process for the
Conventional and Social Networking GroupsConventional Approach

(1) Families are contacted by phone within 48 hours of the infant's death to explain the nonpredictable, non-preventable nature of SIDS, thereby to counter the network's or parents' own blaming. Emergency situations are also assessed in this initial contact and either office or home visits are scheduled.

(2) Counseling, whether in-person or by telephone, is offered to each family, along with the option to attend a monthly parents' meeting. In addition, a public health worker is available to visit the family, usually within one month of the death. This home visit is a supportive, bereavement counseling session where the family's medical and psychosocial needs are assessed. Appropriate referrals are also initiated.

(3) A variety of booklets and articles reviewing SIDS research and discussing grief reactions are mailed to each household. Material is available in more than six languages.

(4) Use of Project services can continue until family terminates service.

Social Networking Approach

(1) All interventions and services offered via the conventional approach are also made available for mothers in the networking group.

(2) With the mother's permission, members of the three network sectors who were perceived as uninvolved or unhelpful were contacted initially by mail with literature explaining SIDS and typical grief and mourning reactions.

(3) Follow-up phone calls and in-person meetings were initiated to reinforce the network members' supportiveness and empathy. Such follow-up was necessary only on a one-time basis, following the initial contact.